“I too matter”. The experience and impact of a brief online self-compassion intervention for informal carers of those with a life-limiting or terminal illness: A mixed methods study

Thesis submitted in accordance with the requirements of the University of Chester for the degree of:

Doctor of Philosophy

by Catherine Jeanne Diggory

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Declaration

"The material being presented for examination is my own work and has not been submitted for an award of this or another HEI except in minor particulars which are explicitly noted in the body of the thesis. Where research pertaining to the thesis was undertaken collaboratively, the nature and extent of my individual contribution has been made explicit".

Signed:  Date: 30th September 2020

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Abstract

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Title of thesis: "I too matter". The experience and impact of a brief online self-compassion intervention for informal carers of those with a life-limiting or terminal illness: a mixed methods study

Aims: Being an informal carer of someone with a life-limiting or terminal illness ('Carer') often results in marked levels of depression, anxiety and stress. Yet, Carers have little available free time to devote to lengthy, well-being interventions offered outside the home. Carers also struggle to prioitorise their self-care, a factor which may help buffer some of the negative impacts of being a Carer. The aim of this research was to gain insight into Carers' views and perceptions of the impact of a brief, four module, online self-compassion intervention for Carers which was created to improve well-being, increase self-compassion and develop self-care among Carers. In so doing, the research addresses gaps in the literature relating to self-compassion interventions for Carers and targeted self-care initiatives for Carers.

Design: This predominantly qualitative study was undertaken in two phases. In Phase One semi-structured interviews with nine participants of a four module, one to one self-compassion intervention (iCare), delivered in person, were conducted and data subjected to a reflexive thematic analysis within a critical realist framework. Additionally, descriptive statistics were collected. The findings from Phase One provided a theoretical basis for the design and content of the online version of iCare, the intervention studied in Phase Two. Seven Carers completed the four module online self-compassion programme. Data were collected through individual module feedback, post-intervention online qualitative questionnaires and descriptive statistics.

Findings: The reflexive thematic analysis of the data generated four overarching themes: **The Myth of SuperCarer**; **Get with the programme!**; '***Being kinder to myself***'; and **Everyone's a winner**. These explored how participants approached iCare-online, the impact engaging with it had on their well-being and highlighted how participants developed self-care through gaining permission to recognise their own needs. Improvements in psychological well-being and increases in self-compassion were reflected in the quantitative findings. In line with critical realist methodology, a causal mechanism was proposed explaining the development of self-compassion and conscious self-care among participants based on a cyclical model of Carer self-compassion.

Implications: This study has relevance for: healthcare practitioners as the findings suggest that these professionals have a key role in legitimising Carer needs and fostering permission in Carers to practise self-care; counselling and psychotherapy professionals who work with Carers who are well-placed to challenge barriers Carer-clients may erect in the face of encouragement to practise self-care and self-compassion. Some of the content of iCare may prove useful to those therapists adopting a pluralistic approach when working with clients who are carers. Finally, teachers of mindful self-compassion could note the importance of the permission-giving aspects of a self-compassion intervention and the role it plays in developing conscious self-care in participants.

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Abbreviations

Caree	An individual with a life-limiting or terminal illness receiving care from a Carer
Carer	An unpaid individual caring for a Caree on an informal basis
CFT	Compassion-focused therapy
CR	Critical realism
DASS	Depression, Anxiety and Stress Scales, 42 item questionnaire
EBT	Existential behaviour therapy
GT	Grounded theory
MBSR	Mindfulness-based stress reduction programme
MND	Motor neurone disease
MS	Multiple sclerosis
MSC	Mindful self-compassion
RCT	Randomised controlled trial
SCS	Self-Compassion Scale, 26 items
TA	Thematic analysis

Chapter One: Introduction

"Man survives because he cares and is cared for"

Wilfrid Gaylin (1976)

1.1 Positioning Statement

Tilly[1] was 40, with three very young children, when she died. She was one of my closest friends and I supported her and her family from her diagnosis and swift decline to death. She was my first real experience of being a 'carer'. A few years later, I helped my mother and siblings nurse my father through a difficult, putrid, terminal cancer. I began to touch the gritty end of caring. There followed more care of a loved dying aunt. By that time, my life-long interest in the mysteries of death and dying combined with these caring experiences, had catapulted me from the corporate world into becoming a counsellor in a hospice working with patients and their families.

I was immersed in the pain, grief, laughter and love present in journeying with someone who is dying and whilst, as a result, I had contemplated my own death (not too painful and time to say my poignant goodbyes) I had not anticipated dying suddenly. I had a brain haemorrhage. I was lucky and I survived without invasive treatment, but I woke up to the fragility of life and the reality that I had not the slightest idea about living 'mindfully' in the moment. This was the starting point of my journey with mindfulness meditation. I trained to deliver the eight-week mindfulness-based stress reduction programme (MBSR) and started to adapt it to bring it to the hospice patients I worked with. My reasoning for this was based on my positive personal experience, the research regarding improved psychological functioning through MBSR, and the possibility of bringing a different quality to patients' living. The standard format of a class of two and half hours per week, over eight weeks, with lengthy meditations, some of 40 minutes duration, was too onerous for the weak and frail patients I worked with. I adapted and shortened the programme and experimented with the content. At the same time, I was deepening my interest in a little spoken about aspect of mindfulness, namely compassion for the self. I learned about a new programme, Mindful Self-Compassion

[1] Pseudonym

(MSC), and avidly absorbed as much training as I could. As a high functioning perfectionist with a severe inner critic, self-compassion touched the parts little previously had been able to reach.

My mother's dementia was worsening, and she was becoming frailer. The family faced the exhausting challenge of supporting her to live and then die at home as she wished. Her behaviour at times was erratic and distressing, complicated by end-stage heart failure. Six weeks before her death, shattered, suffering with insomnia and stressed, I sat for dinner next to, in my eyes, the awe-inducing Kristin Neff (the preeminent researcher into self-compassion and one of the co-creators of MSC). This was the first night of the Mindful Self-Compassion Teacher Training I was attending in the beautiful Shropshire hills near where I was born, and my father's ashes are buried. I was struggling with the direction of my PhD; at that time, I was based within a very quantitative department which paid lip service to qualitative research. Tentatively raising my research ideas with her she encouraged me to pursue my qualitative leanings saying, 'we need qualitative research' in the mindful self-compassion field and just 'add in a couple of pre and post measures'. This brief conversation of no more than five minutes clarified and endorsed the direction I have been taking in this thesis ever since. Buoyed up by the training, I spent the next few weeks supporting my mother and using key self-compassion meditations and practices to support myself in my caring and through her dying.

The experience of using mindful self-compassion as a Carer prompted a refashioning of my mindfulness offerings at the hospice where I worked, so that they became more self-compassion oriented, and became targeted at a previously unaddressed audience – the carers of the patients.

This is the initial framing of motivations for this research. A further exploration of my position as a researcher which endeavours to address Etherington's exhortations to make explicit how my "own thoughts, feelings, culture, environment and social and personal history" (Etherington, 2004, p. 32) inform this research, can be found in Chapters Three and Nine.

1.2 Key Terms

It is important to clarify for the reader the key terms that are used throughout this thesis as the palliative care and carer fields often utilise terms that may appear somewhat bewildering or contradictory to the uninitiated. Hence explanations of a few key terms are offered here before the study is more explicitly contextualised.

The literature around caring for others can be confusing in its use of terms to describe a person who cares. Consequently, the terms '**carer**', '**unpaid carer**', '**informal carer**', '**caregiver**' and '**informal caregiver**' are used interchangeably throughout this thesis to refer to those individuals who offer care in an unpaid capacity as part of a relationship with the cared for individual. To differentiate those caring for someone with a life-limiting or terminal illness from a carer of someone with a chronic illness or disability, the capitalised version of the word is used ('**Carer**') for the former. The person receiving care is defined as a **Caree** in the case of those with a life-limiting or terminal illness. For the sake of clarity those carers who are trained and/or work in a professional capacity and who are generally paid are identified as '**professional carers**' or '**professional caregivers**'.

This research study researches Carers of those with a '**life-limiting illness**' (life-limiting diagnosis). This is an incurable illness that will shorten the life of an individual even though that individual may continue to live with that condition for several years. Examples of life-limiting illnesses include neurological conditions such as multiple sclerosis (MS) or motor neurone disease (MND), dementia, heart failure, chronic obstructive pulmonary disease (COPD) and cancer that is no longer responding to curative treatment (Hospice UK, 2020b; St Clare Hospice, 2020).

When this study was initially conceived, there was a lack of clarity about terminology regarding the meaning of a '**palliative diagnosis**'. The literature referred to 'palliative diagnosis' (e.g. Lordan, Jones, Karanjia, & Butler-Manuel, 2007; Strang, Osmanovic, Hallberg, & Strang, 2018), 'terminal diagnosis' or 'terminal illness' (e.g. DuBenske et al., 2014; Riley & Fenton, 2007) as well as 'life-limiting illness' (e.g. DiGiacomo et al., 2017; Yang, Ewing, & Booth, 2012). The World Health Organization define '**palliative care**' as

a supportive approach focused on improving "the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of … treatment of pain and other problems, physical, psychosocial and spiritual" (World Health Organization, 2020). After consulting with several hospice professionals, the consensus obtained at the time of conception of the study was that generally (although there were exceptions) hospice palliative care was delivered to those with a palliative diagnosis, meaning that the individual was not expected to live more than 12 months. More recently, it appears the term '**terminal illness**' is now more frequently used to indicate the latter stages of a life-limiting illness. The UK Government define a terminal illness as one where an individual has less than six months to live (GOV.UK, 2020a). Notwithstanding this, hospices may refer to a terminal illness as one which has moved to the final or terminal stage of a disease, which is often considered to be the last 12 months of life. Terminology can be used interchangeably as e.g. Marie Curie, the charity offering care and support with terminal illness, conflate terminal illnesses with life-limiting illnesses (Marie Curie, 2020) but do indicate that terms can have different meanings for different people.

In participant recruitment material, reference was made to carers of those with a life-limiting or palliative diagnosis as that was my prevailing understanding of the most appropriate terms to use. In this thesis the reference to life-limiting illness encompasses the terminal phase of that illness, unless the surrounding context suggests otherwise.

1.3 Context of the Research

According to Carers UK (2019b) there are potentially 8.8 million adult carers in the UK of which 42% are men and 58% are women (this includes carers supporting people with a variety of conditions not just life-limiting). Adult carers are most likely to be in the 50-64 age group closely followed by those over 65 (Carers UK, 2019a). Hospice UK state that the hospice sector supports more than 200,000 people with life-limiting or terminal conditions in the UK each year. If we assume that each person has at least one family member or friend caring for them then the number of Carers will be at least that number, but likely to be more as people generally have more than one person caring for them (Hospice UK, 2020a). Furthermore, not every person with a life limiting or

terminal condition is supported by hospice care, particularly in the case of those with non-cancer conditions. For example, it is rare for people with dementia to be caught under the auspices of hospice care despite it being a life-limiting illness. The charity Marie Curie estimated the number of people with a palliative care need using official mortality data (Marie Curie, 2016). The minimal estimate, over the three-year period 2012-2014, in the UK, was 1,150,260 people needing palliative care for conditions such as cancer, heart disease, stroke, dementia. Hence the actual number of people caring for those with such conditions is likely to be similar. On that basis the number of Carers in any one year is feasibly around 380,000 and expected to increase with an ageing population.

Carers make a substantial contribution to the UK economy through providing unpaid care. Wittenberg, Hu, Barraza-Araiza, and Rehill (2019) estimated that there are around 885,000 people over 65 with dementia in the UK, frequently supported by a friend or family member, and that the amount of unpaid care provided represents a cost saving to the UK economy of £13.9 billion annually (Wittenberg, Knapp, et al., 2019). UK modelling research into the cost of caring at the end of life for people with lung, breast, colorectal and prostate cancer estimated that £219 million "of the total costs of care are borne by informal carers in terms of the value of the care they provide and lost employment income" (Round, Jones, & Morris, 2015, p. 902). The likely contribution by all Carers will be significantly in excess of this given the variety of other life-limiting conditions that Carees may have and that Carers provide informal care for. Additionally the research carried out by Round et al. (2015) addressed informal care costs at the end of life. Yet, Carees can live for many years requiring care before they move into the terminal phase of their illness, so this figure clearly under-represents the economic contributions of Carers.

Carers not only make an economic contribution, they also face financial costs in providing care. These may be incurred through such items as travel costs to outpatient appointments including hospital car-parking charges, additional heating costs or buying in extra help with the garden or house. Carers may have to give up work to care. State support is limited and under-valued; Carer's Allowance is currently £67.21 per

week provided that a minimum of 35 hours per week of care is provided, just under £10 per day per Carer for full-time care (GOV.UK, 2020b).

Caring for someone with a life-limiting illness incurs other less quantifiable costs. For example, a 2014 systematic review identified that Carers "were found to have clinically significant levels of anxiety, depression, and perceived stress as well as poorer physical health and decreased quality of life when compared with non-caregivers" (Pottie, Burch, Thomas, & Irwin, 2014, p. 853). The burdens that Carers are under and Carers' various unmet needs are explored in greater detail in Chapter Two, but this brief overview gives some understanding of the pressures that Carers face.

Self-compassion, it is hypothesised, may benefit Carers in terms of improving psychological functioning and overall well-being. To date the research indicates that developing self-compassion as part of resource building has an inverse relationship to psychological distress (Finlay-Jones, Kane, & Rees, 2017), is associated with lower levels of mental health symptoms such as depression and stress (MacBeth & Gumley, 2012; Rudaz, Twohig, Ong, & Levin, 2017) and is negatively related to caregiver burden (Lloyd, Muers, Patterson, & Marczak, 2019).

The term self-compassion in this research study is based on Neff's operationalisation of self-compassion (Neff, 2003b) as comprising three main elements:

> (a) *self-kindness*—extending kindness and understanding to oneself rather than harsh judgment and self-criticism,
>
> (b) *common humanity*—seeing one's experiences as part of the larger human experience rather than seeing them as separating and isolating, and
>
> (c) *mindfulness*—holding one's painful thoughts and feelings in balanced awareness rather than over-identifying with them. (p. 89)

These elements are explored in greater detail in Chapter Two, but they form the foundation of the MSC programme developed by Neff and Germer (2013) which, in turn, forms the basis of the interventions part of this research study. There are other compassion building therapies and programmes but, to date, MSC is the predominant and most well-known intervention targeting the development of self-compassion. It is generally delivered in eight-sessions (2.5 hours per session), plus a half-day 'retreat', which involves a significant amount of participant time. Carers face many constraints on their time as caring for a Caree can be both time-consuming and unpredictable and it is frequently difficult to leave a Caree for any length of time. Consequently, any intervention that is directed at Carers needs to be flexible and minimally demanding of Carers' time and attention. The format of a standard MSC programme is too onerous and protracted for most Carers, hence a brief self-compassion intervention tailored to address Carers was developed. Such an intervention, termed iCare (iCare-online in its online version), is used in this study to explore whether Carers' self-compassion can be developed through a brief, online programme and how self-compassion is perceived by Carers.

The research on self-compassion has rapidly expanded. Since Neff's initial 2003 articles (Neff, 2003a, 2003b), according to a recent search using Google Scholar, there have been over 4,200 entries containing 'self-compassion' in the title. As McGehee, Germer, and Neff (2017) state, most of the research has been quantitative and correlational using Neff's Self-Compassion Scale (Neff, 2003a); there has been little qualitative research which perhaps may explain why Kristin Neff was encouraging about my intention to carry out qualitative research. This is a mixed methods study, but it is predominantly qualitative in nature, the small quantitative element utilised as a way of creating a more informed picture of the operation of self-compassion in Carers.

1.4 Aims and Scope of the Research

This research study aims to better understand:

- if self-compassion in Carers can be developed via a brief online intervention

- what the barriers stopping Carers becoming more self-compassionate are

- if Carers become more self-compassionate, what changes do they notice in their thinking, feeling and doing?

These aims underpin the research question being asked in this study, which is:

What is the impact of a brief online self-compassion programme (iCare-online) on carers of those with a life-limiting or terminal illness?

This research study is divided into two phases. Phase One explores the experiences and views of Carers who participated in a one-to-one face-to-face delivery of a brief, four session self-compassion programme (iCare). The findings from Phase One provide a theoretical and evidential justification for the content and structure of the online version of this programme (iCare-online) which forms part of Phase Two of the study. Phase Two then explores the experiences of Carers who completed iCare-online.

1.5 Researcher's Voice

Within this thesis two perspectives are used, namely the third person and first person. When exploring the literature and commenting on theoretical concepts and the work of other researchers, a third person perspective will be adopted. In line with the interpretivist epistemological position taken, which recognises the interaction between the researcher and the researched (see Chapter 3), the first person will be used when identifying my own ideological standpoint and interpretations.

1.6 Thesis Structure

This current chapter introduces the thesis. In Chapter Two this study is then situated in relation to the relevant literature; I discuss the theoretical underpinnings of self-compassion and critically examine the context of caring in life-limiting illness and outline current practice regarding support for Carers before moving on to briefly discuss the value and challenges of providing online self-help material.

The research methodology is established in Chapter Three including the philosophical and theoretical underpinnings of the study, namely critical realism and a mixed methods methodology.

Chapter Four outlines the research design and method for Phase One of the study including participant recruitment, data collection and data analysis. The qualitative and quantitative findings from Phase One are presented in Chapter Five. These include the themes generated through conducting a reflexive thematic analysis and pre and post quantitative data obtained using two self-report measures. This chapter culminates in a brief discussion of the findings from Phase One and how the findings influenced the design of iCare-online.

The research design and method of Phase Two of the study is outlined in Chapter Six including participant recruitment, data collection and data analysis. Chapter Seven presents the findings from Phase Two which, as in Phase One, include themes generated through conducting a reflexive thematic analysis and pre and post quantitative data obtained using two self-report measures.

Chapter Eight has two parts. Part One of Chapter Eight provides a summary of the findings from Phases One and Two highlighting similarities and areas of difference in the findings and Part Two discusses and critically evaluates these findings situating them within relevant literature and highlighting any new areas that have emerged from the research. This chapter also includes the strengths and limitations of the research and implications for practice.

Finally, Chapter Nine addresses the research question set out above and offers concluding thoughts and reflections about this study.

1.7 Summary

The motivation for this study is to explore the benefits or otherwise of a brief online self-compassion intervention for carers of those with a life-limiting illness, an area not

previously researched. Literature relevant to the research study is critically explored in the following chapter.

Chapter Two: Literature Review

2.1 Introduction

This thesis explores the impact of developing self-compassion in Carers through an online intervention. Contextualising information about this research topic and gaps in the literature are identified in this chapter. It is important first to understand how self-compassion is conceptualised and developed in individuals (**section 2.2**). Whilst the term 'carer' is in common usage, someone caring for a person with a life-limiting or palliative diagnosis faces particular challenges and has specific needs: these are discussed in **sections 2.3** to **2.5**. In order to consider the potential for developing self-compassion in Carers as a way of supporting them, it is useful to see how else Carers are currently supported in the palliative domain and what helps or hinders Carers accessing such support. The literature concerning interventions for Carers is considered and evaluated in **section 2.6**. In **section 2.7** I explore the barriers that can prevent Carers accessing the support they may need. Finally, Phase Two of this study offers iCare in an online format. There are challenges, as well as benefits, to learning new skills online and **section 2.8** provides some context to developing an online intervention for Carers.

2.1.1 Search Strategy

A comprehensive literature search was conducted using the following electronic databases: PsycINFO, PsycARTICLES, PsychBOOKS, PubMED, CINAHL PLUS, MEDLINE, EThOS, University of Chester Library Catalogue and Google Scholar. Some of the key words used to search for literature were 'carer', 'caregiver', 'self-compassion', 'intervention, 'palliative', 'life-limiting', 'online' or 'mindfulness' and an example of a search string used is: unmet needs AND carers OR caregivers OR relatives OR family members AND life limiting OR palliative OR end of life OR terminal illness AND self-care. The titles and abstracts of relevant articles were read, and full texts retrieved if articles were considered to be relevant. To ensure that the results were manageable searches were mainly limited to results from the year 2000 onwards, although in relation to MSC as this is a developing field searches were limited to results from the year 2010 onwards.

Additional searches were conducted on the publications list of the web site of Neff, a key author in the field of self-compassion (www.self-compassion.org), and further relevant references were identified using reference lists, grey literature (i.e. material not published commercially such as reports, leaflets etc. (Ridley, 2012)) and books. Appendix 1 details databases, web sites and search engines used in the literature search together with search terms and search strings.

2.2 Introducing Self-Compassion

This section of Chapter 2 will provide a brief synopsis of self-compassion theory and research linking it to Carer well-being and psychological functioning to situate this study within the current literature.

2.2.1 Understanding Self-Compassion

To achieve a full understanding of the term *self-compassion,* it is useful to start with defining *compassion*. This is not necessarily straight-forward as there is a lack of clarity and agreement about the definition of compassion with, for example, differing dictionary definitions and theoretical debates (Gilbert, 2017b; Goetz, Keltner, & Simon-Thomas, 2010; Kirby, Tellegen, & Steindl, 2017; Strauss et al., 2016). Gilbert (2017b) highlights that within the debate, there are differences between understanding compassion as a feeling or emotion, a motivational state, an attribute or as associated with personality traits. A further exploration of this debate is outwith the parameters of this thesis. In this study, compassion is considered to involve a turning towards the pain and suffering of either self or another with a desire to do something to relieve that suffering, unlike empathy which involves an understanding of what someone else is experiencing (but not necessarily with the motivation to relieve that suffering). In this sense, it aligns with the Buddhist informed definition used in compassion focused therapy (Gilbert, 2014) "*a sensitivity to suffering in self and others with a commitment to try to alleviate and prevent it*" (p. 19).

Note in Gilbert's definition the inclusion of 'self'. This is the essence of *self*-compassion; a gentle, (sensitive) turning towards and recognition of our *own* suffering (pain,

discomfort) with a desire to ease that suffering "and heal oneself with kindness" (Neff & Germer, 2017, p. 371). Self-compassion entails bringing kindness to ourselves regardless of whether our pain is as a result of external circumstances or our own personal failings and inadequacies. Self-compassion recognises that it is part of the human condition to be imperfect, to make mistakes and to suffer (e.g. get old, for you or a loved one to get ill, to lose jobs or relationships etc.). This is what it takes to be human (Neff & Germer, 2017).

2.2.2 The Three Components of Self-Compassion

In Chapter One, I set out how Neff (2003b) operationalised self-compassion, namely as comprising self-kindness rather than self-criticism, common humanity rather than isolation, and mindfulness rather than over-identification. Exploring these concepts further, *self-kindness* involves actively treating yourself with care and understanding at times of difficulty, or when noticing aspects about yourself that you dislike, as opposed to being harshly judgmental and self-critical. When facing external challenges, such as the life-threatening illness of others close to us, self-kindness says focus a little less on problem solving and more on soothing and comforting yourself for the grief and pain you are experiencing.

Common humanity recognises the imperfections of being human, that none of us are perfect, that we make mistakes, and that each and every one of us faces difficulties, pain and suffering at one time or another. Common humanity endeavours to maintain an awareness of the commonality of the human experience rather than what often happens in the midst of suffering, which is a narrowing of perspective, isolating ourselves from connection with others who apparently are living 'happier and problem free' lives. Common humanity encourages a perspective taking of one's position, a realisation that we are not alone in our pain, that others too have faced and are currently facing that which we are going through. In relation to Carers, this is developing an awareness that you are not alone as a Carer, that somewhere within your locality or further afield there are other Carers who are facing the same struggles and pain just like you and who understand what you are facing.

Finally, *mindfulness*, which Neff and Germer define as "being aware of moment-to-moment experience in a clear and balanced manner" (Neff & Germer, 2018, p. 11). Mindfulness is a key part of self-compassion as you need to be able to notice that you are suffering in order to offer yourself compassion. Often people are not aware of the stress or emotional discomfort they are experiencing or, alternatively, they suppress or avoid their pain, which ultimately can be unhelpful and lead to, for example, depression or somatic experiencing. Alternatively, we can exaggerate or become consumed and caught up in our feelings and reactions and lose a sense of perspective, something called "over-identification". Explaining further, "over-identification means that we define ourselves in terms of our behaviors, reifying them as definitive and permanent" (Neff & Germer, 2017, p. 373). Mindfulness permits our seeing our caring situation as it is, neither more burdensome nor less than it is.

The development of these three facets of self-compassion comprise the bedrock of the Mindful Self-Compassion ('MSC') programme created by Kristin Neff and Christopher Germer, (Germer & Neff, 2019; Neff & Germer, 2018; Neff & Germer, 2013) which in turn influenced the development of iCare. Whilst there are other compassion development programmes available, it is only MSC that specifically focuses on building self-compassion.

Criticisms of Neff's construct of self-compassion have been made (López et al., 2015; Muris & Petrocchi, 2017), it also differs from Gilbert's focus on competencies (Gilbert, 2017a) and there is some confusion as to whether self-compassion is in fact a facet of other-focused compassion (Strauss et al., 2016). Notwithstanding these criticisms, Neff's original definition of self-compassion remains the most used in research studies (Muris & Otgaar, 2020) and in the recently published The Oxford Handbook of Compassion Science it was the only definition of self-compassion proffered (Seppala et al., 2017). It seems that Neff's conceptualisation of self-compassion currently predominates given the lack of a commonly accepted alternative.

2.2.3 Self-Compassion and Well-Being

Over the last decade there has been a growing body of literature about compassion, self-compassion, compassion focused therapies and self-compassion interventions. Given the limits of this thesis it is not possible to review all the extant literature across these areas. Rather this part of the review concentrates on self-compassion research as it relates to the health and wellbeing of Carers. Studies investigating compassion focused therapy ('CFT') (e.g. Gilbert, 2010a, 2014) have been excluded as CFT is generally directed at clinical populations with severe mental health problems, with CFT being used for the treatment of e.g. eating disorders, depression, shame and other severe mental health problems (Gilbert & Procter, 2006; Judge, Cleghorn, McEwan, & Gilbert, 2012; Kelman, Evare, Barrera, Muñoz, & Gilbert, 2018). Additionally, the underpinning theory of CFT is different from that of MSC as it is based upon evolutionary and social psychology. MSC differs in that it includes elements of resource building and personal development training with elements of Tibetan Buddhist practices.

The following studies highlight the potential value that improving self-compassion may have on Carer well-being and psychological functioning, albeit that they do not focus on Carers directly. The cultivation of self-compassion has been linked to improved mental health and well-being. Van Dam, Sheppard, Forsyth, and Earleywine (2011) reported on the possibility of self-compassion being a predictor for psychological health. Whilst it involved a large sample size (n= 504), this was a correlational study, although participants ranged from 18 to 73 years of age, such an age range more likely to encompass Carers. Other research indicates that there are physiological benefits to developing self-compassion such as reducing stress responses (Arch et al., 2014; Breines et al., 2014), which is directly relevant to the Carer position. Whilst the latter two studies demonstrate the potential self-compassion may have as a buffering factor against social evaluative stress and stress-induced inflammatory responses, the mean age of participants was between 19-21, reducing the relevance of these studies to Carers. In a more recent study, two short-term self-compassion exercises (11 minutes in duration) compared with three control conditions were used to test self-reported mood and psychophysiological responses of a group of students. Results indicated that, in line with previous research, self-compassion "activates an emotion-regulation system that has

been associated with calm and content positive affect, soothing, and social affiliation" (Kirschner et al., 2019, p. 16) and thus may have some positive impact on well-being and psychological functioning. This is in line with Neff's original thoughts that self-compassion could be a useful strategy for regulating emotions (Neff, 2003b), something which may be valuable to Carers given the emotional demands of caring. Yet participants were students, not faced with the burden of caring, albeit they may have been experiencing their own personal difficulties. Thus, the results may not be directly applicable to Carers. Other studies suggest that self-compassion is a negative predictor for anxiety and positively associated with psychological well-being (Neff, Kirkpatrick, & Rude, 2007) and seems to help people moderate the effects of negative events (Leary, Tate, Adams, Allen, & Hancock, 2007) all of which could be beneficial for Carers.

A number of meta-analyses have examined features of self-compassion. MacBeth and Gumley (2012) examined associations between self-compassion and psychopathology and reported large correlations between higher levels of self-compassion and lower levels of mental health symptoms such as depression, anxiety and stress (r=.54). Another meta-analysis found that there was a strong positive relationship between self-compassion and well-being (r=.47) with there being a stronger relationship for cognitive and psychological well-being compared to emotional well-being (Zessin, Dickhäuser, & Garbade, 2015).

Self-compassion has also been examined as it relates to functioning in clinical populations, which whilst not directly relevant to the Carer position adds some insight into its operation in stressful, demanding situations. It has been linked to a better adjustment to living with HIV including lower stress, anxiety and shame (Brion, Leary, & Drabkin, 2014), and clinically significant reductions in depression and positive metabolic effects among patients with diabetes (Friis, Johnson, Cutfield, & Consedine, 2016). In a mixed sample study of over 200 cancer patients, patients with chronic illness and healthy subjects, Pinto-Gouveia, Duarte, Matos, and Fráguas (2014) found that self-compassion was linked to reduced symptoms of stress and depression, and better quality of life especially in patients with cancer. There is also some evidence for an

association between levels of self-compassion and reduced symptoms of post-traumatic stress disorder (Winders, Murphy, Looney, & O'Reilly, 2020).

In relation to carers more widely, the research is limited. Self-compassion has been linked to reduced psychological distress in parents of young people and adults with learning disabilities, suggesting that self-compassion may play a part in building resilience (Robinson, Hastings, Weiss, Pagavathsing, & Lunsky, 2018). In Carers of people with dementia, Lloyd et al. (2019) found that that those Carers reporting higher levels of self-compassion experienced reduced caregiver burden compared to those with lower levels of self-compassion (p. 54).

Overall, the literature is sparse regarding research into the links between self-compassion and Carers. Yet the wider research indicates there is some evidence to suggest that developing self-compassion could benefit Carers helping to support them in their caring role and it provides support for building self-compassion in Carers. The 'how' of developing self-compassion is explored below.

2.2.4 Measuring Self-Compassion

In the previous section the literature relating to the links between self-compassion and well-being, with particular reference to the well-being of Carers, has been explored. If an intervention is said to be impactful in terms of developing self-compassion, and potentially well-being, in Carers then it will be important to assess changes in levels of self-compassion pre and post an intervention. The most commonly used measure for assessing self-compassion is that of the Self-Compassion Scale (SCS) (Neff, 2003a), developed in both a 26-item and 12-item short form version (SCS-SF) (Raes, Pommier, Neff, & Van Gucht, 2011). Either version is reported to have been used in over 95% of empirical studies of self-compassion (Muris & Otgaar, 2020).

Yet there is an ongoing debate between Neff and a number of other researchers (e.g. López et al., 2015; Muris & Otgaar, 2020; Muris & Petrocchi, 2017) regarding whether the SCS actually measures self-compassion. There is particular disagreement about the use of a total self-compassion score for the SCS; some researchers argue that in fact the

elements in the SCS that comprise compassionate self-responding should be highlighted separately from those that comprise uncompassionate responding e.g. self-judgement, isolation and over-identification. This would then provide for a more nuanced understanding of the development and impact of both compassionate and uncompassionate responding. Recently Muris, Otgaar, López, Kurtic, and van de Laar (2020) suggested that in fact the SCS assesses vulnerability and not the protective aspects of self-compassion. Neff has not yet responded to this criticism but her earlier rebuttals to criticisms of the use of a total self-compassion score (e.g. Neff, 2020a; Neff, Whittaker, & Karl, 2017) and research of others (Cleare, Gumley, Cleare, & O'Connor, 2018) support the use of a total self-compassion score. Further details of the SCS measure are provided in Chapter Four, Section 4.6. In this study a total self-compassion score together with individual sub-scale scores are reported addressing concerns raised about the use of a total self-compassion score.

More recently newer self-report compassion measures have been developed. Gilbert et al. (2017) developed three new measures of compassion which include a self-compassion element. This measure is based on an evolutionary, motivational approach. However, the definition of self-compassion on which this measure is based differs from that underpinning MSC. The Sussex-Oxford Compassion for the Self Scale (Gu, Baer, Cavanagh, Kuyken, & Strauss, 2020) is a newer development but again is based on a different conceptualisation of self-compassion to the one used by Neff. As such these outcome measures were considered to be less useful to the current study as they would not be directly assessing the factors that the intervention used in this study aimed to target.

2.2.5 Developing Self-Compassion

Whilst self-compassion can be considered an inherent personality trait, research also suggests that self-compassion can be augmented through training. As seen above, mindfulness is one of the key components of self-compassion and one way of developing self-compassion is through specific training in mindfulness. MBSR (Kabat-Zinn, 1982) is the most widely known and researched of the mindfulness based interventions. Whilst MBSR does not have a specific self-compassion component, MBSR teachers do

emphasise warmth and kindness in their teaching and encourage a kindly self-orientation. Several studies have shown that self-compassion increases following MBSR interventions (Birnie, Speca, & Carlson, 2010; Irving, Dobkin, & Park, 2009; Shapiro, Astin, Bishop, & Cordova, 2005; Shapiro, Brown, & Biegel, 2007), and analyses corroborated the association between self-compassion, positive psychological functioning and reduced negative emotions. Increases in total self-compassion in these studies, as measured by the SCS, ranged from 16-22%.

As mindfulness-based interventions tend not to specifically target the development of self-compassion, Neff and Germer created the MSC programme - with the hypothesis that such an intervention could boost self-compassion more than mindfulness based interventions (Neff & Germer, 2013). MSC follows a similar format to that of MBSR, namely eight weekly sessions of around 2.5 hours per session with a half-day silent meditation retreat. The programme includes a variety of formal compassion-based meditations, informal self-compassion practices and in-class discussions all designed to develop self-compassion. Participants are encouraged to practise up to 40 minutes per day of either the formal meditations or informal practices.

The first reported research of the eight week MSC programme is that of Neff and Germer (2013) who conducted a randomised controlled trial (RCT) of the MSC programme. They found that participants increased their levels of self-compassion by 43%, as well as reduced levels of anxiety, depression and stress. Neff and Germer raise several limitations with the research, including that nearly three quarters of participants in the programme had previous meditation experience which may have impacted the results and self-report measures were used. These results were corroborated with a later study which used a brief self-compassion intervention of three group meetings of around three hours duration in total for female college students. Informal self-compassion exercises were used rather than formal meditations. Results indicated a 21% increase in self-compassion compared to an active control, with a large effect size (Smeets, Neff, Alberts, & Peters, 2014). Interestingly the intervention did not impact mood, but the authors suggested that it may take longer for a stronger effect on mood to emerge (p. 803).

Targeting professional carers Delaney (2018) conducted a study of the eight-week group MSC programme for 13 nurses. Results indicated that the programme reduced secondary trauma and burnout which were negatively associated with self-compassion. Total self-compassion increased by 24% pre to post intervention. In light of nurses' misgivings about self-compassion (see Andrews, Tierney, & Seers, 2020), achieving such an increase in self-compassion is worthy of note. Yet, this was a small-scale study with no control and no longitudinal phase, and the limited qualitative element did little to amplify the findings. Other studies of the MSC programme with patients with cancer or diabetes or clinical and health psychology trainees (Brooker et al., 2019; Friis et al., 2016; Yela, Gómez-Martínez, Crego, & Jiménez, 2019) reveal the range of increase in self-compassion that can be obtained with the eight week model, namely from 6% to 23% (self-compassion as measured by the SCS).

Yet the evidence supporting the value of targeting self-compassion is generally based on small sample sizes, as highlighted in the meta-analysis carried out by Kirby et al. (2017) which examined the effects of RCTs of compassion-based interventions (including MSC-based) over a number of outcome measures. Whilst there were significant differences in change scores on self-report measures pre and post of such items as self-compassion, depression, anxiety, psychological distress and well-being (results maintained when including active control comparisons), the underpinning evidence relied in the most part on small sample sizes.

Not all agree that it is useful to specifically target developing self-compassion. Challenges have been made questioning the effectiveness of this approach. Wilson, Mackintosh, Power, and Chan (2018) identified, in their systematic review and meta-analysis of the effectiveness of 'self-compassion related' *therapies,* that 'self-compassion therapies' produced improvements in self-compassion, anxiety and depressive symptoms. Yet, when the analysis was restricted to studies of 'self-compassion related' therapies with active control conditions, unlike Kirby et al. (2017), they found that change scores were *not* significantly different. The authors concluded that "the emerging picture is that self-compassion-related therapies do not have a special role to

play in promoting self-compassion, either as an end in itself or as a means of influencing other psychological characteristics" (Discussion section, para. 3). The conclusions from this meta-analysis have been hotly contested (Kirby & Gilbert, 2019), not least because the selected therapies for inclusion in the search process and meta-analysis were not all specifically self-compassion or compassion focused (most of the included studies were mindfulness-based studies). MSC (Neff & Germer, 2013), the intervention most pointedly centred on self-compassion, was excluded from the analysis. It is important to note that MSC (which underpins the intervention the subject of this research) was not designed as a therapy and is not taught as a therapy. The latest meta-analysis of 27 RCT's of self-compassion interventions (which included three MSC based interventions) (Ferrari et al., 2019) indicated moderate effects for increases in self-compassion and reductions in, inter alia, depression, stress and anxiety.

Of relevance to this study is that the research of self-compassion-based interventions is, in the main, quantitative in nature. Whilst assessments have been made of changes in self-compassion and symptology, there is little that explores an individual's perceptions of growing self-compassion, how this may feel, and how it is manifested in their lives. This study addresses this deficit.

At the same time as research of the MSC programme has grown, research has also been conducted into adaptions of MSC including shorter interventions, novel self-compassion trainings and online self-compassion training. As the interventions used in Phases One and Two of this study are both brief (Phase One) and online (Phase Two) a closer examination of the research in these areas is now offered.

2.2.6 Online and Brief Self-Compassion Trainings

As we have seen, the original mindfulness based and MSC programmes were delivered in an eight-week format with weekly sessions of around 2.5 hours per session plus a retreat half-way through. Since their conception mindfulness and self-compassion interventions have been modified into briefer formats and taken online. This is of relevance to this study as Carers have little available time. Supportive interventions need to meet their time needs and requirements for flexibility. Consequently, modified

deliveries may hold promise but clearly such interventions need to be useful. There follows an overview of the evidence regarding the acceptability and usefulness of such interventions for caregivers (both formal and informal). Mindfulness-based interventions are included as they mirror some of the aspects of course delivery seen in self-compassion focused interventions and point to feasibility and acceptability of brief interventions.

One of the most relevant studies to map onto Phase Two of this study, in terms of content and mode of delivery, is that of Finlay-Jones et al. (2017). They examined a novel six-week, self-paced online self-compassion course based on an emotion regulation model of self-compassion for Australian psychology trainees (n=37, 89% female). This involved a module per week taking between 1-2 hours per module plus homework. Results indicated an increase in total self-compassion, as measured by SCS, of 24% and significant improvements in happiness, stress and symptoms of depression although not anxiety (as measured by a number of measures including DASS-21). The lack of impact on anxiety could be due to participants being a non-clinical population so base levels of anxiety may have been low to start with. Changes were maintained at 3-month follow up. Of consideration is that participants were psychology trainees. This may have predisposed them to being more open to learning something which may have potential value in their clinical work, compared to non-psychology student participants who may have been less motivated to persist with an online intervention. In another non-clinical population (n=31), a short-term online 'Emotion Focused Training for Self-Compassion and Self-Protection' significantly increased self-compassion scores. The intervention consisted of participants responding to emails delivered over 14 days requesting them to complete certain self-compassion and self-protection tasks (Halamová, Kanovský, Varšová, & Kupeli, 2018). It did contain elements of, inter alia, the MSC programme but there was no personal interaction with participants.

Further evidence in support of a brief online self-compassion intervention was the study from Eriksson, Germundsjö, Åström, and Rönnlund (2018). This involved an RCT of a brief web-based intervention aimed at reducing stress and burnout in practising psychologists. Increases in self-compassion scores, as measured by SCS, of 18.52%,

showed a large effect size in the intervention group (n=51). Most participants were female with over 66% reporting little to no mindfulness training in the preceding 3 months. The 'tunnelled' intervention (i.e. participants had to complete one lesson before they were able to move on to the next) was a 6-week programme based on 15 minutes training per day, 6 days per week with a predetermined sequence of exercises to be completed. Content included exercises based on mindfulness and compassion for self and others together with auditory files of guided instructions. Whilst the study title refers to 'Mindful Self-Compassion Training', the content was not directly based on Neff and Germer's MSC programme (2013). The authors commented that both the increases in self-compassion and reductions in perceived stress and burnout were comparable to results obtained in face to face deliveries of similar interventions (p. 7).

The above studies offer some support for the usefulness of brief online self-compassion interventions in general, but they were not targeted at Carers. The following studies of online interventions are more pertinent to the present study as they relate to carers but they are predominantly mindfulness based. Qualitative data highlighted the value of an online intervention for partners of cancer patients, 9 out of 14 of which were described as having life-limiting diagnoses (Köhle et al., 2017). This was not a pure self-compassion intervention and the self-compassion elements did not mirror those of MSC (this study is explored in more depth in **section 2.6.4**).

Online mindfulness-based interventions for caregivers of non-palliative patients have shown some positive results with significant improvements in depression and anxiety symptoms with small to medium effect sizes (Hearn, Cotter, & Finlay, 2019). This did involve a twice daily practice commitment and the intervention was spread over eight weeks. In another study of an online mindfulness intervention for older adult caregivers, reductions in caregiver burden, perceived stress, anxiety and loneliness were reported. Again, this was in an eight-week format (Tkatch et al., 2017). Both studies offer some support for the feasibility of online meditation interventions for Carers, although Hearn et al. (2019) do suggest that future studies should look at developing brief interventions that are more easily adapted into day-to-day life to reduce conflicting with carer responsibilities. There is some evidence indicating the value of brief, limited

mindfulness interventions. Mindfulness training of four hours over four weeks was shown to reduce caregiver burden in dementia caregivers (Hoppes, Bryce, Hellman, & Finlay, 2012). More generally, two systematic reviews of brief mindfulness training offer encouraging evidence that positive changes in well-being, including stress and anxiety and healthcare outcomes can be achieved with brief training including single sessions and short interventions of only five minutes duration (Gilmartin et al., 2017; Howarth, Smith, Perkins-Porras, & Ussher, 2019). Yet these systematic reviews did not specifically address studies involving Carers so it is unclear how such brief trainings could impact Carers.

Clearly there is little literature on either mindfulness-based, or self-compassion-based online and/or brief interventions for informal carers in the palliative field. What literature there is does appear to support that online and brief interventions are acceptable to caregivers generally and may have some effect on well-being, although most outcome measures are self-report in nature and the research is generally quantitative.

2.2.7 Fears and Obstacles to Self-Compassion

Although findings from research indicate that being more self-compassionate has a number of beneficial effects, some people fear and mistrust self-compassion leading to resistance. Neff and Germer (2017) suggest five reasons why self-compassion may be opposed. For some being self-compassionate is considered a weakness (perceived as a soft and fluffy concept); other objections to self-compassion include it can lead to laziness, it is self-indulgent, narcissistic and selfish. Neff and Germer rebut these assumptions, arguing that, for example, self-compassion is anything but weak or self-indulgent and can involve making courageous decisions to implement say healthy habits or step away from abusive situations; yet these suspicions arise frequently enough to need specific attention in any self-compassion training. Other researchers in the field concur that self-compassion can be seen as a weakness by some, which can be linked to abusive backgrounds or to those with high levels of shame (Gilbert, McEwan, Matos, & Rivis, 2011; Gilbert & Procter, 2006). It may produce fearful or avoidant reactions, forming part of a fear that some people have of positive emotions in general, again in

part due to aversive backgrounds. A further concern about self-compassion is that it may undermine our motivation to achieve - in relation to Carers this could be interpreted as a fear that through becoming more self-compassionate, caring standards drop and the Caree will suffer. The research does not support this, suggesting instead that self-compassion actually enhances motivation to achieve (Breines & Chen, 2012; Neff, 2003a).

In the context of Carers, the most probable misgiving about self-compassion is that it is perceived as selfish, which is likely to challenge the self-concept Carers may hold as an all-giving, selfless support to the Caree. Neff and Germer counter the concern about selfishness, arguing that through being more caring and supportive to yourself, in turn you have greater emotional resources to give to, in this instance, your Caree. Currently, the evidence is unclear as to whether those who are more self-compassionate are, as a result, more compassionate to others (Neff & Pommier, 2013). Where there is clearer research, is regarding the link between self-compassion and burnout which, as I argue later, could be relevant to the Carer experience. Neff and Germer (2017) suggest that whilst there are many people who are more compassionate to others than themselves, this way of being is unsustainable, leading to burnout. The research is more robust in this area but focused on professional caregivers such as counsellors, healthcare practitioners or chaplains. It suggests that higher levels of trait self-compassion are linked to less compassion fatigue, reduced burnout and stress with greater role satisfaction (Barnard & Curry, 2012; Hashem & Zeinoun, 2020; Newsome, 2010; Newsome, Waldo, & Gruszka, 2012; Shapiro et al., 2005; Shapiro et al., 2007). To date, there do not appear to be any studies examining the impact of self-compassion on levels of burnout and stress in Carers. By extension from the research involving professional caregivers, it could be assumed that self-compassion might operate in a similarly protective fashion as it does with that group of caregivers.

Perhaps, in part as a response to these common misgivings about self-compassion, Neff has added a further dimension to her understanding of self-compassion introducing what she terms the 'yin and yang' model of self-compassion (Neff, 2019b). This model highlights not only the tender, healing aspects of self-compassion (yin), but also the

active, providing, motivating or fierce protective aspects (yang), about which less has been spoken, but which involve an empowered clarity of action and a motivating encouragement to take better care of yourself. This new model is at the early stages of dissemination and, to date, there is no research differentiating these two aspects of self-compassion. Future research into the yang aspect may aid in overcoming the picture some hold of self-compassion as something which is weak and insubstantial.

Developing self-compassion can be difficult with little or no understanding of what it actually means to be self-compassionate. Pauley and McPherson (2010) explored the meaning and experience of self-compassion in a clinical population of people with depression and anxiety. Whilst self-compassion was considered to be a useful and meaningful concept, it was perceived to be challenging to become self-compassionate when you had no, or little, experience of it and "that developing the psychological skills associated with this concept would be extremely difficult" (p. 137). These findings were further supported by the qualitative study of Campion and Glover (2017) into a non-clinical population's response to a brief self-compassion intervention. Several barriers to self-compassion were identified from the 12 participants (pp. 1104-5):

- Self-compassion does not fit with current norms and expectations
- There's not enough time [to be self-compassionate]
- Self-compassion creates feelings of guilt and vulnerability
- Society needs to permit self-compassion first [the need for permission from others to be self-compassionate]

As participants were drawn from a non-clinical population, similar barriers may be anticipated in the participants in the present study.

One of the core concepts in the qualitative study of nurses' experiences of self-care and self-compassion undertaken by Andrews et al. (2020), similarly parallels that of Campion and Glover (2017) in stressing the need for permission for self-compassion (to come both internally and externally): a barrier to getting this permission was the viewing of self-compassion "as a weakness and therefore, potentially problematic" (p. 6). This matches one of the misgivings about self-compassion that Neff and Germer raise and Gilbert and Procter (2006) identified. Shame can also be a barrier to and inhibitor of self-compassion (Gilbert & Mascaro, 2017; Gilbert & Procter, 2006) be that internal shame based on our own negative and critical evaluations of ourselves or external shame where "we experience *others* as seeing oneself as inadequate, flawed, undesirable, unattractive or bad in some way" (Gilbert & Mascaro, 2017, p. 409). If clinical, non-clinical and professional caregiver populations struggle with the concept of self-compassion then it is highly probable that Carers may too.

2.3 Who are the Carers?

In Chapter One, I contextualised the UK position of Carers setting out the contribution they make supporting people with life-limiting illnesses. But what 'makes' a carer more generally? Bowlby (1997) proposed that, as humans, we are born with an innate tendency to protect and support those who are "either chronically dependent or temporarily in need" (Mikulincer & Shaver, 2017, p. 190). This is an evolved behaviour organized by a caregiving behavioural system (Solomon & George, 1996) that has developed to protect the tribe, particularly young dependents. This behaviour is motivated by the imperative of seeing the transmission of shared genes via reproduction, by caring for dependents through to reproductive maturity. This system, proposed Mikulincer and Shaver (2017), extended to close family members; generally it is assumed that it is easier to offer care and support to those who we are closest to either biologically or psychologically. The urge to care for others, it is argued, also arises from social motivations "embedded in human nature and rooted in evolutionarily developed brain systems that we share with other mammals" (Colonnello, Petrochhi, & Heinrichs, 2017, p. 105). Hence, it appears that to care for others is ingrained within the human psyche (unless of course the caregiving system has developed under negative influences such as disruptions in parental-child bonds). This is a wide subject area outwith the

scope of this thesis but is touched upon here to give a limited theoretical background to caring motivation in general.

The 1970's saw the emergence of the term 'carer', with ideas about what it is to be an 'informal carer' or 'family carer' influenced by professional caring perspectives. Academic research interest in carers grew out of feminist and sociological literature in the 1980's and 1990's with caring determined as a gendered activity (Henwood, Larkin, & Milne, 2017; Larkin & Milne, 2014).

The Royal College of General Practitioners define a carer as follows:

> *A carer is a person of any age, adult or child, who provides unpaid support to a partner, child, relative or friend who couldn't manage to live independently or whose health or wellbeing would deteriorate without this help. This could be due to frailty, disability or serious health condition, mental ill health or substance misuse* (Royal College of General Practitioners, 2019)

A narrower definition, focused on illness and introducing emotional care work, is that of NICE (2004) which state that carers "may or may not be family members, are lay people in a close supportive role who share in the illness experience of the patient and who undertake vital care work and emotion management" (p. 155). Researchers have adopted similar definitions focusing on the care and support provided by family members and friends to the cared-for individual (e.g. Dharmawardene, Givens, Wachholtz, Makowski, & Tjia, 2016; Sin et al., 2018) with Sutanto et al. (2017) specifically highlighting that carers have a "significant relationship" (p. 23) with the cared-for person; the relationship aspect is often implicit in other definitions. Within UK derived health and social care literature the term 'carer' has been widely adopted and even enshrined in UK law, e.g. "Care Act" (2014).

Awareness of carers and their contribution to the UK economy and health budget has grown, not least in part, due to the active carers movement in the UK (e.g. Carers UK,

Carers Trust), and whilst the term 'carer' may be widely used, particularly within a medicalised setting such as the UK hospice movement, the term 'carer' is not without its critics. The term can be imbued with a sense of burden which may negatively impact the cared-for person in terms of inferring dependence (Olson, 2015). It can be criticised for generalising a personal experience which varies, for example, depending upon the type of care being provided, the amount of care, the relationship between the person providing the care and the cared-for, and the cared-for's needs and dependency (Larkin & Milne, 2014).

Others suggest disregarding the term completely given that "it is a mark of bureaucracy" (Molyneaux, Butchard, Simpson, & Murray, 2011, p. 422), transmogrifying a normal part of a relationship into a convoluted 'thing' to be observed and explained (see also Hughes, Locock, & Ziebland, 2013 regarding bureacratising the role of carer). Furthermore Molyneaux et al. (2011) propose that 'carer' is merely a concept comprising both social and political factors less connected to the relational and emotional aspects of caring but focused on claims to practical support (p. 423).

Some people find it hard to accept the label of carer (this is explored further in **section 2.7.2**), seeing caring as an inherent part of their role as partner, offspring, friend, etc. 'Hidden carers' are those who do not willingly embrace the label of carer and the term can also include sub-sets of carers such as "older carers; young carers; rural carers; carers from Black and minority ethnic groups (BAME), and carers in other groups that may be 'below the radar', including those in lesbian, gay, bisexual and transgender (LGBT) relationships" (Social Care Institute for Excellence, 2019). In some cultures, there is no concept of a 'carer' (Glasby & Thomas, 2018; Molyneaux et al., 2011), seeing caring as part of the inherent responsibilities of familial relationship. This may be a stereotyped view as some research challenges the assumption, for example, that "South Asian people live in self-supporting extended families, and therefore, that the support of social services is largely unnecessary" (Katbamna, Ahmad, Bhakta, Baker, & Parker, 2004, p. 404). Researching some of these hidden carers can be problematic as they can be difficult to identify due to support services lacking cultural awareness of their existence (Henwood

et al., 2017) and cultural and language barriers may mean a failure by such carers to access services.

2.4 The Burdens of Caring

The carer-focused literature is predominantly framed within a 'burden of care' discourse (Henwood et al., 2017). The sense of carer burden, suggest Ellis-Hill and Payne (2001), is derived from professionals conflating informal caring responsibilities with their own professional caring responsibilities, which are then expanded outside the work day to 24 hours/day care. Hence the common conception of informal caring being onerous and emotionally demanding. Ellis-Hill and Payne (2001) caution that seeing informal caring as an extension of professional caring may mean this leads to a medicalised model of informal caring.

Nearly 20 years later, Carers are frequently involved in essential medical and personal care at home (e.g. medication/injection administration, tube feeding, symptom monitoring, intimate personal care, checking oxygen supplies, using equipment to aid transfers from bed to chair to toilet etc.), which can make it difficult to see that Carers are so much more than proxy nurses/health-care assistants as they do provide an emotional and social input that professionals are unable to bring. This may explain, as will be seen below, why some professionals can be seduced by the good medical care provided by Carers and fail to address some of the emotional and psychological needs of Carers. As a charity offering care and support for terminal illness, Marie Curie comment "Carers are not trained professionals, and they should not be expected to behave as such" (Marie Curie, 2015, p. 19). Yet in the Covid-19 pandemic Carers were being expected to administer end of life medication including subcutaneous injections (Hill, 2020; NHS England, 2020).

Whilst the burdens of being a Carer are explored below, there are some that argue for a more positive view of caring, such as Nolan (2001). More recently, others have commented on the paucity of research into the positive aspects of caring and suggested that Carers hold both positive and negative feelings about their caring role (Henriksson,

Carlander, Årestedt, & Årestedt, 2015; Henwood et al., 2017). In their own research into palliative Carers' experiences, Henriksson et al. (2015) found that Carers reported high levels of reward based on feelings of being helpful to the Caree and of bringing them "happiness and being there for them" (p. 1509). This is in line with a recent scoping review of qualitative studies exploring the positive aspects of caring for a person with dementia which highlights many beneficial aspects such as role satisfaction, emotional rewards of feeling appreciated and reciprocity in giving back or repaying the love and care the Carer has previously received (Lloyd, Patterson, & Muers, 2016). Clearly, feelings of reward will be dependent upon the quality of the relationship between Caree and Carer.

The evidence does support several negative aspects arising from being a Carer, and the concept of carer burden will now be explored. Choi and Seo (2019) attempted to bring clarity to the multidimensional nature and construction of caregiver burden in palliative care, proposing that this concept:

> *is attributed to the perception of physical symptoms, psychological distress, impaired social relationships, spiritual distress, and financial crisis that arise from caregiving tasks or care demands. Disruptive to a caregiver's daily life, caregiver burden involves role strain and increases the level of uncertainty during palliative care* (p. 287)

Carers provide much support to those they care for, e.g. physical, emotional, financial, administrative, but this is particularly true of those caring for someone with a life-limiting or terminal diagnosis when the intensity of care generally increases as the Caree's health deteriorates towards the end of life. The amount of care that Carers provide is significant, with it rising towards the latter stages of the Caree's life, with levels of reported care being in the region of 63-69 care hours per week (Buscemi, Font, & Viladricht, 2010; Rowland, Hanratty, Pilling, van den Berg, & Grande, 2017). Caring for more than 50 hours per week may be linked to poorer physical and mental health (Carers UK, 2019b). Physical care can take its toll on Carers, with Carers experiencing fatigue, particularly if sleep patterns are disturbed which often occurs (Maltby,

Sanderson, Lobb, & Phillips, 2017). In addition to the physical and emotional care that Carers are providing they are also holding their own feelings of fear, loss and anticipatory grief, as well as adjusting to changing roles and changes to relationships (see Badr, 2014). Tierney, Tutton, and Seers (2019) highlight the loss of a Carer's personhood and the impact on all aspects of life, including emotional and physical well-being, that Carers of those with dementia may experience through caring. The early work of Pearlin, Pearlin, Mullan, Semple, and Skaff (1990) highlights the losses inherent in being a Carer, and the stress of 'relational deprivation' or 'the deprivation of intimate exchange', which can be found in caring relationships when the Caree becomes more poorly, or even when they receive the initial diagnosis. Whilst both Pearlin et al. (1990) and Tierney et al. (2019) were writing about the caring situation as it relates to people with dementia, there is no reason to believe that these losses and stresses would be any less pertinent to Carers of Carees with other diagnoses. As Pearlin et al. (1990) state, "The sheer dramatic and involuntary transformation of a cherished relationship is itself a major source of stress" (p. 584).

Hence, it is of little surprise that across the research Carers consistently report increased levels of stress, anxiety and depression. A recent narrative review added more support for high rates of psychological distress and burden experienced by Carers (Oechsle, 2019). Generally over 30% or more of Carers participating in research have moderate to high levels of anxiety, and just under 30% of Carer participants have clinically significant levels of depression (Götze, Brähler, Gansera, Polze, & Köhler, 2014; Götze et al., 2018; Pottie et al., 2014; Washington, Demiris, Pike, Kruse, & Oliver, 2014). In an Austrian study of 345 advanced cancer carers, nearly 52% of Carers had one or more suspected 'psychiatric' disorders with anxiety the most common (Rumpold et al., 2016). Spouses and parent Carers exhibited most symptoms. Amongst informal carers in England (thus not necessarily carers of those with a life-limiting diagnosis), 61% reported being stressed, 45% depressed and 78% tired (NHS Digital, 2019).

There is some evidence to suggest that women experience a higher degree of burden than men (Mystakidou et al., 2013; Schrank et al., 2016), with younger female Carers more likely to be anxious than their older counterparts or male Carers (Washington et

al., 2014). In contrast, Choi and Seo (2019) found that the evidence was mixed regarding the burden of care vis a vis men and women, with some studies reporting higher levels of Carer burden in women than men, and others vice versa. Schrank et al. (2016) reported that, for women, a significant predictor of higher burden was being in employment whilst caring, contradicting Washington et al. (2014) who found that being in employment was a buffer against anxiety.

There seems to be more agreement that spouses and parents experience higher levels of burden and distress than other Carers (DiGiacomo et al., 2017; Götze et al., 2014; Rumpold et al., 2016).

Whilst much of the research into Carers has focused on those caring for individuals with advanced cancers, it is useful to highlight that when Carees move into the ambit of hospice care, there appears to be little difference between non-cancer Carers and cancer-Carers in terms of quality of life and levels of anxiety experienced by Carers (Washington, Pike, Demiris, & Oliver, 2015). However, differences in Carer burden may appear with different Caree diagnoses. This may be as a result of prolonged periods of care with illnesses with longer trajectories, such as dementia, allowing for greater time for Carers to adjust to a diagnosis compared with generally shorter periods of care with palliative stage illnesses, where the illness may have advanced more quickly and Carers having little time to adjust. Yet, with illnesses with a longer disease trajectory, care may be more protracted and thus more burdensome. There is some evidence to suggest that end of life caring is more intense than medium to longer term care-giving resulting in greater negative impacts (Williams, Wang, & Kitchen, 2014). In contrast, Wittenberg-Lyles et al. (2012) concluded that longer periods of caring (e.g. of people living with dementia) resulted in the biggest negative impact on mental and physical health of carers.

One concern that is often mentioned in the literature, is that Carers' own health begins to suffer through caring. Researchers warn that as distress becomes overpowering, this can impact not only on the Carer's quality of life, but also the quality of care that they provide to the Caree; this, in turn, can impact health care systems as more resources are

required to support both the Carer and the Caree (Hampton & Newcomb, 2018; NICE, 2019a; Rumpold et al., 2016).

There are a number of factors which support Carers and buffer against the caregiving burden and these include having social support, a lack of financial concerns and a sense of meaning in providing care and hope (Götze et al., 2014; Pottie et al., 2014). Recently, Lloyd et al. (2019), in a study of 73 Carers of people with dementia, identified that Carers with higher levels of self-compassion experienced less caregiver burden than those Carers with lower levels, which offers some support to interventions targeting developing self-compassion in Carers.

2.5 The Needs of Carers

The previous section has explored the burdens that Carers may experience in their caring role. Is there anything that can mitigate against these burdens? Within the palliative care field, there has been recognition of the importance of Carer needs and how meeting these can better support Carers, minimise caregiving burdens and, in so doing, help to maintain both Caree and Carer wellbeing. Sutanto et al. (2017) suggest that failing to address Carer distress and unmet needs can result in impacts on Carer health and mental well-being. Similarly, Longacre et al. (2018) concluded that unmet needs not only impact the caregiver, but also impact the patient through reduced quality of informal care and impact on the patient's mood. These latter findings should be treated with caution as they may not be specifically applicable to the palliative care arena, as the research focused on cancer family caregivers, and is not limited to those with a palliative diagnosis.

The caregiving literature refers to the 'unmet needs' of carers. What are these? They can be defined "as the difference between the services or support required to deal with a particular challenge and the actual services or support received" (Girgis, Lambert, Johnson, Waller, & Currow, 2013, p. 1557). Carer needs tend to fall into one of three categories: Social, Practical or Emotional/Psychological (e.g. Ewing, Grande, & National Association for Hospice at Home, 2013; Glasby & Thomas, 2018; Hashemi, Irajpour, & Taleghani, 2018; Wang, Molassiotis, Chung, & Jing-Yu, 2018). Examples of these needs

are shown in Table 1. Note self-care is not included in this table other than in relation to Carer physical health.

Table 1

Examples of Carer Needs

Social Needs	Practical Needs	Emotional/Psychological needs
Maintaining social networks	Information Needs: • Practical advice/training on the 'how' of caring (e.g. equipment handling, personal care) • Advice on symptom monitoring & management • Advice on medication administration • Financial/work/benefits advice • Exploring dying process	Support with feelings including: • anxiety • depression • anger • frustration • guilt • hopelessness • grief • helplessness
Networking with other Carers	Support in decision-making	Managing trauma (watching loved one in pain, distress)
Reducing Isolation & loneliness	Managing Carer fatigue/sleeplessness	Existential distress
Managing competing needs within families	Respite & practical support	Spiritual distress
	Dealing with Carer's own physical health issues	Being 'seen' and 'heard' by healthcare professionals
		Facilitating conversations with Caree regarding prognosis/end of life

In addition to the studies referred to above, there have been several other studies reporting on the extent of Carer needs and how these are met, or not, by healthcare professionals. Some Carers refer to the lack of affirmation of their role and their contribution within the patient's healthcare network by professionals; so that despite their insider status with expertise and intimate knowledge about the Caree and their illness they still remain invisible (Anderson & White, 2018; Seal, Murray, & Seddon,

2015). For others, the role of Carer brings social isolation (Foster et al., 2015; Hughes, Noyes, Eckley, & Pritchard, 2019) as they become more tied to home, given increasing levels of care and dependency of a Caree with declining health. Carer needs may also vary depending upon whether care is taking place at the patient's home or, e.g. at a nursing home; in the latter there is less need for practical information, but Carers are more likely to need support with other needs (Wittenberg-Lyles et al., 2012).

Despite a developing awareness of Carer needs within palliative care, the growth in number of various interventions to support Carers (see **section 2.6** below), and the creation of tools to assess Carer needs (e.g. "CSNAT. Carer Support Needs Assessment Tool,"), the needs of family Carers are generally given insufficient attention. Assessment of Carers within UK hospices is patchy with 47% of hospices using informal assessment of needs which could be as basic as asking how the Carer is (Higgerson, Ewing, Rowland, & Grande, 2019). Palliative care services do "not offer proactive care and access to supportive resources… (e.g. training, respite care, access to resources)" (Ateş et al., 2018, p. 1). Similarly a recent narrative review of literature between 2016-18 reported Carers had an "alarmingly high number of unmet needs" (Oechsle, 2019, p. 1).

What appears to be missing from most research is a focus on the self-care needs of Carers and, as the intervention the focus of this study promotes Carer self-care, this is worthy of further exploration.

2.5.1 Is There a Need for Carer Self-Care?

Self-care is a nebulous term which lacks consistent understanding, although the term is in common usage particularly in self-help discourses of 'taking care of yourself'. A recent Google search for the term "self-care" produced what appeared to be over one hundred million results. A similar search on Amazon UK produced over 100,000 results. Self-care can be variously defined and is generally framed within a discourse of a way of coping. It can also be seen as a way of being (Breiddal, 2012; Rudaz et al., 2017) or as a way of health promotion and developing well-being (Mills, Wand, & Fraser, 2017).

Few studies that examine the global nature of carer needs address the need for self-care, and little literature has been found which addresses the self-care need of Carers in particular. Within the palliative care field, the literature is more concerned with researching the self-care strategies, practices and training interventions for healthcare professionals e.g. doctors, nurses and therapists, particularly as it is recognised as an area of work which is emotionally, physically and spiritually challenging with significant levels of burnout. Generally, the research into self-care is couched within a framework of preventing or recognising professional caregivers' burnout and compassion fatigue (e.g. Harrison et al., 2017; Mills et al., 2017; Tucker, Bouvette, Daly, & Grassau, 2017). As these terms may be relevant to Carers, I offer a brief explanation of burnout and compassion fatigue.

Burnout manifests itself in poor performance at work, absenteeism, increased staff turnover and, on an individual basis, physical, emotional and mental exhaustion, lowered immune functioning, poor sleep patterns, gastrointestinal disorders to name a few of the symptoms experienced (Ayers & de Visser, 2018; Delaney, 2018). Compassion fatigue, like burnout, is often associated with healthcare practitioners, particularly nurses. Figley (2002) described compassion fatigue as evolving from secondary traumatic stress, similar to emotional contagion and vicarious traumatisation, adding that compassion fatigue was a form of burnout. It seems surprising then that there is a dearth of research into Carer burnout and compassion fatigue, and the value of self-care, when Carers might be expected to be potentially vulnerable to the pressures of these phenomena as they care for a seriously ill/dying loved one. This is particularly so as, unlike professional carers, there is no 'clocking off' from their responsibilities. As seen in **section 2.4**, Carers experience significant levels of emotional and psychological distress resonant of burnout but this does not appear to be reflected in the literature. Searches of abstracts between the period 2010-2019 conducted using the keywords "self-care", "burnout OR compassion fatigue" OR "secondary traumatic stress OR vicarious traumati*ation OR emotional contagion" together with variations of "palliative care" and "carer" produced two references to Carer burnout (see below) and three references to Carer self-care with other results focused on patient self-care or professional caregivers self-care.

Of the two references identified for burnout, Ostlund, Wennman-Larsen, Persson, Gustavsson, and Wengström (2010) used a burnout measure as part of their study of the mental health of Carers of those dying of lung cancer, identifying that approximately 40% of the 84 participants reported symptoms of strain on this measure. Flechl et al. (2013) reported that 60% of participant Carers "stated burnout problems", although the study does not specifically identify what these 'problems' are. Identified outside the results of this search, Merluzzi, Philip, Vachon, and Heitzmann (2011), in their study of the feasibility of The Caregiver Inventory (a measure of self-efficacy for caregiving), comment that the omission of self-care in existing caregiver self-report measures "reflects a degree of oversight of what may be a critical component in preventing caregiver burnout" (p. 16). There appears to be an awareness of the concept of Carer burnout, but research of it is limited.

Three studies were identified that referred to Carer 'self-care':

- Applebaum, Farran, Marziliano, Pasternak, and Breitbart (2014) identified that cancer caregivers' self-care, inter alia, was a contributor to caregiver burden. Worthy of note is that whilst 20% of *carers* identified self-care issues as contributing to caregiver burden only 6% of *patients* recognised caregiver self-care as a contributor. If the patient fails to see the impact and import of carer self-care, then it may be additionally harder for carers to motivate themselves to prioritise self-care without patient support. Detailed information about self-care was not included in the study and the carers in this study were not caring for someone with a life-limiting or palliative diagnosis.

- Sun et al. (2015) reviewed the effectiveness of a family caregiver palliative intervention that made mention of personalised self-care plans aimed at improving quality of life but detail about self-care itself was lacking despite mention being made of 'the self-care concept' and even though support with self-care was identified as key to improving Carer well-being (p. 3738).

- Hampton and Newcomb (2018) approached self-care from a different perspective. In their study of 78 palliative caregivers, findings point to the significance of Carers' self-care needs in building self-efficacy ("an individual's belief in her/his ability to carry out activities and tasks specific to caregiving" (p.472)). Self-care, it is suggested, is a particularly vulnerable element of self-efficacy, echoing Merluzzi et al. (2011). As global self-efficacy is seen as having a "significant correlation with stress" (p. 471) any susceptibility to self-efficacy is worthy of further exploration. In this study those participants with the highest confidence in taking care of themselves had the lowest levels of perceived stress. Not only is this important for Carer welfare but, as Hampton and Newcomb hypothesise, low levels of confidence in self-care may result in the failure of Carers to take care of themselves sufficiently well enough resulting in exhaustion "and increased personal, physical, mental, and emotional health problems for caregivers" (p. 475). This in turn could result in reduced level of efficient caring, leading to hospital admission for the Caree or other unforeseen health care costs, not to mention the additional costs which may be incurred in supporting the Carer.

  Given the priority that Hampton and Newcomb's place on self-care in the role of self-efficacy it is not surprising that they endorse the introduction of interventions that nurture and support Carer self-care.

Falling outside the initial search strategy, but identified from adopting a snowballing approach to cited references, Acton (2002) identified that Carers of those with dementia participated in fewer health-promoting self-care activities than non-caregivers and that those who did practice more self-care experienced reduced effects of stress. A meta-analysis of interventions for carers of those with cancer (but not necessarily advanced cancer) found that 77% of interventions reviewed addressed self-care but the attention given to self-care content varied considerably; it was often a secondary focus of an intervention and fewer interventions focused specifically on carers' self-care (Northouse, Katapodi, Song, Zhang, & Mood, 2010). Whilst the authors proposed that

more studies were needed to explore carers' self-care practices and the impact these had, some 10 years later this suggestion seems to have been largely ignored.

Dionne-Odom et al. (2017) found that low levels of self-care practice were strongly associated with poorer carer anxiety, depression and mental health related quality of life (p. 2442). In this study, self-care was assessed over six domains: taking responsibility for your own health; participating in exercise; balanced nutrition; spiritual growth; mutual caring relationships with others; taking steps to manage stress levels (p. 2440). This was a quantitative study of 294 American carers of those with a poorer cancer prognosis, but not limited to life-limiting or palliative patients. The average age of participants was 66 years and predominantly White and female. Hence it is not known what approach to self-care younger, male and/or different ethnicity of carer may have adopted. Family caregivers' (though not of those with a life-limiting diagnosis) personal self-care activities were also found to have a direct relationship with emotional well-being and general health (Pope, Giger, Lee, & Ely, 2017).

In summary, the very limited research suggests that Carers show evidence of burnout and that increasing self-care practices may reduce Carer burden, lower stress, anxiety, depression and improve mental health. It seems clear that the area of Carer self-care is under-researched which is disappointing given the potential improving self-care may have for buffering against some of the negative effects of caregiving. **Section 2.7.3** below explores some of the obstacles to Carer self-care.

2.6 Palliative Care Supportive Interventions for Carers

Within the palliative care field, it is now widely recognized and accepted that the informal caregiver plays a pivotal role in supporting the Caree. As the recognition of the Carer's role has widened, research into Carer needs and burdens has expanded (with a focus on Carers of those with a cancer diagnosis) and specific Carer targeted interventions have been developed to address these needs.

The literature exploring interventions supporting caregivers is wide and comprehensive with much research carried out in the field of informal caregivers of those with cancer.

This section addresses some of the literature in this area as much of the research may be transferable to the field of Carers of those with a life-limiting or palliative diagnosis, whether of advanced cancer or other illnesses such as dementia or MND. As technology has advanced in recent years, so has the variety of, and the research into, technology-based interventions including web-based interventions and e-health interventions. The literature about these forms of caregiver interventions is reviewed in **section 2.6.3** particularly as it pertains to Phase Two of the study.

Studies researching counselling and psychotherapy for Carers have been excluded from this review, unless they specifically included elements of mindfulness or self-compassion, as whilst this form of support is commonly offered to patients, families and Carers within palliative care settings it is not directly comparable with a psycho-educational intervention which is the focus of this study.

2.6.1 General Interventions

In 2005, there were few studies researching interventions for Carers (McMillan, 2005). Since that time the numbers of supportive interventions for Carers and those caring for those with serious illness (mainly cancer) have increased and are wide ranging in approach. These include psychosocial interventions such as psychotherapy addressing existential distress and spiritual well-being with mindfulness skills (Applebaum, Kulikowski, & Breitbart, 2015; Fegg et al., 2013; Kögler et al., 2015), family based psychosocial interventions (Badr, 2014), interventions that target improving coping skills, problem solving skills, enhancing well-being and reducing caregiver stress (Candy, Jones, Drake, Leurent, & King, 2011; Northouse, Williams, Given, & McCorkle, 2012; Sutanto et al., 2017), or more idiosyncratic interventions such as music therapy (O'Kelly, 2008) or afternoon tea get-togethers (Parsons & Anderson, 2009). The format of interventions varies from in person group support, interventions for the patient-Carer dyad or one to one sessions with a professional, such as a social worker or psychotherapist.

2.6.2 Efficacy of Interventions

Whilst interventions for Carers may be a developing field, what is less clear is the efficacy and impact of these interventions. A decade ago, Hudson, Remedios, and Thomas (2010) in their systematic review of psychosocial interventions for Carers, argued for improvements in the quality and quantity of research studies. Greatest emphasis was placed on what they saw as the strongest evidence, namely rigorous quantitative evidence, with qualitative research relegated to playing a role in reporting on developments in the field (p.2). The systematic review undertaken by Epiphaniou et al. (2012) of interventions for carers of those with cancer or receiving palliative care reported an accelerating number of robust intervention studies but with a limited range of intervention models. The comparable intervention models to iCare reviewed were the one to one psychological models (generally supportive or psycho-educational in nature). Out of the eight studies of this form of intervention, only two 'high quality' RCT studies demonstrated a significant treatment effect and that was for "positive rewards of caring" (p 10). A later systematic literature review of hospice services for Carers added to this call for more research into efficacy of interventions despite some encouraging outcomes (Pottie et al., 2014). Whilst examining interventions for patients with advanced cancer and their families, (thus not specifically targeting caregivers), Badr (2014), in her narrative review of family interventions, identified that whilst modest improvements in caregiver burden were seen these were generally not maintained over time. A more recent review of interventions for Carers of palliative cancer patients highlighted the increase in the number of available interventions but added to the call for more evaluated interventions and robust empirical evidence of effectiveness (Sutanto et al., 2017). The findings did indicate though that interventions do generally improve the psychosocial outcomes of Carers.

Latterly, attention has focused on the ability to implement interventions, addressing such outcomes as feasibility, acceptability and appropriateness (Ugalde et al., 2019). Whilst Ugalde et al.'s systematic review looked at cancer caregiver interventions rather than interventions for Carers of palliative patients, some interesting threads were highlighted, not least the low participation rates across studies (feasibility outcome), noting that less than one third of eligible carers agreed to participate in studies. These are caregivers of those with a potentially curative diagnosis. The challenges Carers face

are conceivably greater, given the emotional, existential and psychological demands they endure, and thus it may be thought likely that take up rates may be even lower in this population. Ugalde et al. (2019) suggest that this low take up indicates that interventions are not sufficiently focused on caregivers most in need but rather adopt a broad-brush approach.

This mixed picture of varying evidence regarding the value and impact of interventions and the lack of evidence pointing to any one intervention being more efficacious than another is highlighted by the most recent report by NICE (2019b) on end of life care, which noted that the evidence supported:

> *… a potential positive effect of supportive interventions on both patient and carer quality of life, with improvements also seen in quality of life proxies such as depression and depression (sic) and reduced carer burden. However, given the inconclusive findings from a number of studies and the heterogeneity of interventions, the Committee were unable to recommend any single carer support service* (p. 46)

2.6.3 Technology-Based Interventions

As iCare-online, the intervention the subject of Phase Two, is a technology-based intervention this section explores the evidence for these forms of Carer interventions. The research predominantly focuses on carers more widely than Carers.

Technology has developed over recent years and so has interest in utilising it to increase the variety of caregiver interventions, particularly as it seen as a flexible, convenient way of supporting caregivers, especially those that may be housebound or live in rural locations. Additionally, there may be cost benefits in reducing the number of staff involved in delivering interventions through the use of technology. Earlier research, such as Applebaum and Breitbart (2013), highlighted that newer modalities for delivering interventions, for example, internet-based interventions, or using Skype to communicate with caregivers, could bring benefits, but required further study to understand better the challenges and potential benefits of these forms of interventions.

Some of the earlier uses of technology have included transferring a nurse-led patient-carer psychoeducational programme for cancer caregivers to a web-based three session format with similar findings (e.g. improved caregiver self-efficacy) between the two formats, although the web-based format did not have a control group (Northouse et al., 2014). Other early developments included a self-guided cognitive behavioural internet intervention for cancer caregivers (Scott & Beatty, 2013), telephone, video interventions (Chi & Demiris, 2015) and various other web based psychosocial interventions (Badr, Carmack, & Diefenbach, 2015). However, there have been calls for more evidence as to the efficacy and impact of such interventions on caregivers (Kaltenbaugh et al., 2015; Slev et al., 2016).

The quantitative evidence continues to be less than fully convincing regarding the effectiveness of technology-based interventions for carers generally. A recent systematic review (Guay et al., 2017) examined quantitative studies of internet-based interventions for caregivers of older adults encompassing caregivers of those with dementia and cancer. Significant reductions in caregiver depression and anxiety were seen in only four out of the 12 studies reviewed. Whilst the effective interventions used a variety of components including online exercises, homework, remote human support via professionals or peers and behaviour change techniques it was not possible to identify which component led to the improvement in caregiver outcomes. The results of this review echo those of Chi and Demiris (2015) which reported that in 44% of the 61 quantitative studies of telehealth tools and interventions for non-palliative family caregivers reviewed, psychological health (including depression, anxiety, stress and caregiver burden) significantly improved. Studies across both reviews were predominantly USA-based.

Unusual in including qualitative and mixed methods designs along with quantitative studies, Sin et al. (2018) undertook a systematic study of eHealth interventions for family caregivers of those with long term illness. It should be noted that 'long term illness' included illnesses relevant to this thesis, such as dementia or cancer, but also brain injury or mental disorder, which are unlikely to fall under the ambit of a 'life-limiting' illness. Studies were predominantly USA-based with a wide variety of approaches such

as online therapies (e.g. CBT, counselling, coaching) either delivered with or without network support, problem-skills training or writing/journal therapy. Psychoeducation was identified as the most popular intervention. Interventions were found to be acceptable to caregivers due in part to their flexibility and the ability for caregivers to go at their own pace with interventions. Yet reported treatment effects on caregiver outcomes, such as self-efficacy, quality of life and caregiver burden, showed a significant positive effect in only 32% of the included studies.

Finally, Heynsbergh, Heckel, Botti, and Livingston (2018) examined feasibility, usability and acceptability of technology-based interventions for informal advanced cancer carers in their systematic review of studies which examined new software interventions. They tentatively concur with Chi and Demiris (2015), Guay et al. (2017) and Sin et al. (2018) when they state that their findings suggest that interventions are appropriate and "that web-based interventions may have a positive impact on carers' social and psychological wellbeing" (p. 10). As in these other reviews most studies reviewed were conducted in the USA. Whilst the evidence base is developing, additional studies are being called for to further explore the effectiveness of technology-based interventions (Demiris, Washington, Ulrich, Popescu, & Oliver, 2019; Heynsbergh et al., 2018; Marzorati, Renzi, Russell-Edu, & Pravettoni, 2018; Shin, Kang, Noll, & Choi, 2018).

Regardless of whether technology-based interventions are effective or not, Carers must be willing to participate in them. Views conflict about carers' interest in such interventions. In one European study of intention to use web-based psychological interventions (n=168), 53% of partners of those with cancer (but not palliative) were not interested in such interventions; of those that expressed some interest they tended to be younger and more frequent users of the Internet (Köhle et al., 2018). One of the reasons given for rejecting the idea of such interventions was their perceived impersonal nature. Yet in a much smaller study of Carers' preferences for a supportive online programme based on self-compassion and mindfulness (a pre-cursor to iCare-online) two-thirds of the 18 participants (mean age 56, 10 male, eight female) indicated they would be willing to use technology to access a training programme online with a clear preference for a self-paced version. One of the main barriers to participation in such an

intervention was a perceived lack of technical competency rather than concern over lack of personal connection (Diggory, 2015). Other research suggests that older adults may in fact be more comfortable using technology and online interventions for health purposes than was previously thought e.g. LeRouge C, Van Slyke C, Seale D, and K. (2014); Schneider et al. (2018). In these latter two studies participants were not Carers and under the pressures that Carers live with, which may affect willingness to use technology-based interventions.

Technology-based interventions appeal to some, but take-up is mixed and the impact variable which concurs with the findings of NICE (2019b). As Demiris et al. (2019) remind us, such interventions come with challenges including ethical challenges about maintaining confidentiality and accessibility challenges. The research is predominantly quantitative, based on the carer experience more widely and offers little to provide nuanced explanations of if and how technology-based interventions of any kind prove valuable to Carers.

2.6.4 Mindfulness and Self-Compassion Interventions in Palliative Care

The research into interventions based on mindfulness and/or self-compassion for carers (not specifically palliative carers) is limited. Neff, the pre-eminent self-compassion researcher, provides a comprehensive list of studies about self-compassion either authored by herself or others on her personal web site www.self-compassion.org (Neff, 2019a). Research is categorised into subject areas, and it is noteworthy that at the date of access of the 55 studies listed under 'Self-Compassion, Caregiving and Burnout', (the subject area closest to this study), 51 studies centred on professional caregivers such as nurses or social workers, or students of professional caregiving trainings including nursing students, medical students and therapists/counsellors in training. Of the remaining four studies, two researched self-compassion as it related to being a parent of a child on the autism spectrum and one of caregiving generally as a parent. The only study identified to research Carers was Danucalov, Kozasa, Afonso, Galduroz, and Leite (2017) which involved a RCT of a yoga and compassion meditation programme for 25 family caregivers of people living with Alzheimer's disease. This was an eight-week programme utilising three yoga/meditation sessions per week, one face to face, the

other delivered via use of a DVD in the caregiver's home. The intervention offered did not contain any exercises or meditations from the MSC programme and did not appear to have content particularly directed at building self-compassion. 28% of participants dropped out due to lack of time as a result of their caring responsibilities. Total self-compassion scores, as measured by the Self Compassion Scale ('SCS') (Neff, 2003a) increased by approximately 6.75% with other statistically significant increases in other domains including quality of life. This does not represent an exceptional increase in self-compassion given the time commitment of participants and as it was a quantitative study it is impossible to tease out the nuances of what improved quality of life or increased self-compassion represented to the Carer participants.

Neff's summary of self-compassion-based research reflects the outcome of the literature search strategy in this thesis. Very few studies have examined the role of self-compassion in informal carers' well-being, with most research directed toward professional caregivers. In the field of life-limiting and terminal illness to the best of my knowledge there are no studies exploring a pure self-compassion training (either brief or standard MSC delivery) for Carers. The nearest to such an intervention is that of Köhle et al. (2017). This is one of very few qualitative studies of a self-compassion intervention in the healthcare field for informal carers. It explored partners of cancer patients' (9 out of 14 with life-limiting diagnoses) experiences of using a web-based intervention based upon Acceptance and Commitment Therapy ('ACT') and self-compassion. The content of the intervention is referred to as having self-compassion components, but these do not map on to the MSC programme.

The Köhle et al. (2017) study stands out as an isolated example of both a qualitative study and one that targets Carers, and as such, it is explored in greater depth. The intervention involved six lessons, plus one optional lesson, 'tunnelled' to the next lesson. Lessons comprised text, various brief psychological exercises based on ACT and self-compassion and a downloadable "mindfulness exercise based on self-compassion" (Köhle et al., 2017, p. 6). Support was available if participants were in either the automated support condition (automated feedback straight after completing an exercise) or in the personal support condition in the form of an email message reflecting

on progress from a "personal online counsellor" (p. 6). It is not fully clear the type/content of the counsellor training as the counsellors were described as "trained masters psychology students" (p. 6) under supervision of a researcher and clinical psychologist which leaves it unclear as to the depth of their counselling training. Whilst participants were generally supportive of the intervention and reported finding some helpful processes, there were mixed responses to the support received including the content of the counsellor feedback and the 'tunnelled' structure. Of the six participants who did receive personal support, five provided comments, four were less than positive expressing disappointment at the lack of tailored personal feedback rather than feedback on their progress with the intervention which was what they received.

The qualitative analysis appears to have been conducted within a more positivistic framework with emphasis placed on coding reliability, inter-coder agreement and frequency of reported codes with no mention of the epistemological or ontological positions adopted. Even so it was insightful to gain a snapshot of participant experiences as it highlighted the importance of authentic personalised support to the participants. The authors concluded that despite the misgivings expressed by some participants, overall, this web-based intervention "based on ACT and self-compassion may be a valuable contribution in supporting partners of cancer patients" (p. 1). Further studies are warranted to substantiate this assertion given the results were not wholeheartedly supportive.

Mindfulness-based interventions for Carers do not appear to produce as significant results as those compared with the general population. Murfield, Moyle, and O'Donovan (2019) identified, at June 2019, 32 studies of mindfulness- and compassion-based interventions for carers of older adults. Most studies were of interventions for carers of those living with dementia and none of the interventions included MSC based studies. In the main, interventions studied were MBSR, mindfulness-based cognitive therapy and 'meditation' interventions, generally adapted with shorter sessions and less intense homework requirements, appearing to be delivered in a face to face format. The evidence base did not warrant any claims to effectiveness. In similar vein, a systematic review of mindfulness-based interventions for informal palliative carers (Jaffray,

Bridgman, Stephens, & Skinner, 2016) found that whilst interventions may reduce depression and caregiver burden "effects were not as robust as findings in the wider mindfulness intervention literature" (p. 117). Interestingly in a move away from the reliance on quantitative research, calls for more qualitative research were made in order "to more richly explore the perceived effects identified by informal palliative caregivers themselves, which may be missed if we presuppose particular outcomes" (p. 127). The qualitative aspects of the present study aim to 'richly' illuminate any perceived effects of self-compassion training through the iCare interventions.

Currently there is insubstantial evidence to support a definitive picture that mindfulness or self-compassion-based interventions are of value for Carers.

2.7 What Stops Carers Seeking Help?

There are a variety of supportive interventions on offer for Carers and yet take up is mixed and in some cases noticeably low. The reasons why this might be so are explored below.

2.7.1 Barriers to Interventions

Whilst there may be a variety of interventions created to support Carers, it is important to be aware of the barriers that Carers may face or place in front of themselves to prevent accessing supportive interventions. Carduff et al. (2014) identified in their literature review and analyses of focus groups with researchers, health professionals and Carers, three main categories of barriers that can hinder Carers accessing support. Firstly, there can be a slow dawning that individuals are actually Carers; this may be particularly true for those caring for others with an often-slower disease trajectory such as dementia or MS compared with a late diagnosis of rapidly advancing cancer. In the former case Carers may have a blind spot around their identity as a carer as care input builds over many months or years (Ateş et al., 2018). Carduff et al. (2014) suggest that in fact Carers see themselves in a relational role e.g. partner, son or daughter rather than as a Carer and their research suggests that it takes a health professional to highlight to them that they are in fact a Carer. A second barrier highlighted that as the demands of caring for the Caree increased as their illness progressed, Carers' own needs were subsumed under the burden of meeting those increasing demands. Carers were unable to meet both their

own needs and that of the Caree, placing priority on the Caree's needs. The third barrier identified was the ambiguity surrounding whose professional responsibility it is to identify Carers in the community. This, linked with the Carer's own confusion about where to access support and with some GPs identified as failing to be proactive in supporting Carers, deterred Carers from asking for help. Carers also may need the recognition and endorsement of front-line professionals before they accept that they are in fact 'Carers' (Carduff et al., 2014; Corden & Hirst, 2011).

Caregivers of advanced cancer patients are inclined to ignore their own self-care needs as their sense of identity is subsumed within their role as Carer (Broady, 2017; Nissim et al., 2017; Riley & Fenton, 2007). This may in part be due to Carers considering their role to be less important than that of the Caree and that as such their needs are not a priority (Badr, 2014; Heynsbergh, Botti, Heckel, & Livingston, 2019; Ream et al., 2013). Others suggest that Carers are ambivalent about meeting their needs (Harding & Higginson, 2001). This unwillingness to address your own needs could come from an altruistic perspective, described by Fisker and Strandmark (2007) as Carers keeping the "loving promise" (p. 274) made to partners to allow them to die at home whatever the cost to the Carer. Carers may also face a further barrier as some literature has reported that Carers perceive that most support is targeted specifically at patients, ignoring the needs of Carers (Nelson, Mansfield, & Kane, 2017; Nissim et al., 2017). Whilst a small-scale study, Nissim et al. (2017) identified that Carers' preferences are for a resource that is specifically focused on their needs and which can be accessed separately from the cared-for.

Harding and Higginson (2001) talk about the ambivalence Carers have regarding their own unmet needs, that is, a simultaneous attraction to and aversion to meeting those needs which paralyses Carers from taking action to meet their needs (p. 644). They propose that any intervention for Carers needs to address this ambivalence and "work with their [Carers'] lack of identification, provide safe and legitimate time and space, be time limited (i.e. not add to the anxiety of being away from the patient) and be respectful of their existing coping strategies" (p. 644). Whilst this study was nearly 20

years ago their views of Carer interventions still seem to be relevant and there is no convincing evidence their proposals have been fully implemented.

2.7.2 Identity - to be or not to be a Carer

To take up the offer of a Carer-focused intervention, one must first recognize one's self as a Carer. As seen above for some Carers the transition into 'Carer' happens so gradually that they do not see themselves as a Carer (Carduff et al., 2014); instead they stay rooted in the relational role of, for example, partner, sibling or daughter/son. Harding and Higginson (2001) describe this as a failure to self-identify as a Carer; rather the relational role of care is based on a notion of duty to the Caree and is a part of being in relationship with the Caree (part of being a member of their individual family unit). To then assume an identity as 'Carer' may be uncomfortable to some and may pose a challenge to the role of partner or son/daughter (Corden & Hirst, 2011).

Despite the increasing awareness of the concept of caregiving and the important role that informal carers play in society, recently encapsulated in legislation ("Care Act, 2014,"), designation as a 'Carer' by and large depends on self-characterisation as such (Corden & Hirst, 2011; Harding & Higginson, 2001). Failure to self-identify may then mean that opportunities to take up applicable health and support services on offer are missed (Andreasson, Andreasson, & Hanson, 2018; Carduff et al., 2014; Corden & Hirst, 2011; Olson, 2015). In addition to the assumption of the identity of Carer it may be that some Carers fail to recognize that by providing valuable emotional support as opposed to daily physical and personal care they are still caring.

For some Carers accepting the label of 'carer' is to accept the bureaucratisation of the relational role that they have (Hughes et al., 2013; Olson, 2015) by falling into what Olson et al. characterise as "the figured world of cancer" (p.178). This can be described as moving into the 'cancer' (or other illness) system. Olson argues that, from her study, spouses were less likely to accept the nomination as Carer if they were still in a reciprocal relationship with the spouse, that is, there were still emotional and interactive connections with each other and thus this dichotomy between 'carer' and cared-for was spurious (Henwood et al., 2017). Once this reciprocity diminished,

spouses were more likely to accept that they had moved into a 'carer' role, but a spouse's married identity was also given priority as this automatically subsumed care responsibilities as part of the spousal duty to care for each other.

What does not appear to be addressed is the implication for unmarried partners, and whether they have as strong an attachment to the role and identity of partner (with inherent caring obligations) as married couples do. It should be noted that Olson's study addressed 'cancer care-giving', which may not necessarily encompass advanced/palliative cancer-care. The element of 'reciprocity' is challenged by the findings of Seal et al. (2015), who found that in spousal relationships where cancer was present the husband/wife roles were converted into carer/patient with no mention of a gradual transition or loss of reciprocity. Yet they do refer to the difficulties which occurred as carer and cared-for adjusted to the assumption of new identities and balanced these with their other identities as partner and carer. Losing the identity as 'husband', 'wife', 'daughter' or 'son' was perceived as the main concern with being identified as a carer (Hughes & O'Sullivan, 2017) albeit this study was focused on carers more generally.

Other reasons for rejecting the identity of Carer may include that in doing so the Carer is accepting that the Caree is actually ill and in need of care and neither the Caree nor the Carer may be able to accept this (Carduff et al., 2014). This is echoed by the Hughes and O'Sullivan (2017) study of Irish carers, who found that carers were respectful of the person being cared for, not wishing, by accepting the designation carer, to emphasise the cared-for's need for care. Carers also rejected the term carer for its failure to encompass the breadth and scope of the caring role. Other evidence contradicts these findings, suggesting that the carer identity is more easily accepted. Seal et al.'s (2015) meta-synthesis of qualitative studies challenges the struggle with identity previously highlighted. This was a meta-synthesis review of the findings of 17 studies of carer experiences of those with cancer. 12 out of the 17 studies focused on carers of those with palliative or terminal diagnoses or those who had died at the time of the study or studies where some of the participants were caring for those in the palliative phase of their illness (i.e. relevant to this study). Unlike studies referred to earlier, a carer identity does

not appear to be disputed as Seal et al. (2015) do not highlight any struggle with the adoption of carer identity in their findings, merely suggesting reasons for the assumption of such an identity ("cultural, societal, or professional expectation …as well as a perceived obligation or duty to their ill relative" (p.498)).

The difficulty is that if people do not see themselves as Carers they will be unlikely to seek out interventions specifically targeted at Carers and thus miss out on helpful, resilience building resources; health care professionals need to be sensitive to this reluctance to self-identify as a Carer and encourage take-up.

2.7.3 Barriers to Self-Care

Carers are sometimes encouraged to care for themselves by health professionals, but there is evidence to suggest that Carers are poor in practising self-care (Dionne-Odom et al., 2017; Nissim et al., 2017). Yet what does it mean to practise 'self-care' when you are not the patient but the caregiver? It has been suggested that a definition of self-care is multifaceted and complex (Godfrey et al., 2011). Their research examined self-care predominantly as it related to patient self-care, but they proffer a useful definition applicable to Carers. After tracking the development of the concept over several decades, they propose that "Self-care involves a range of care activities deliberately engaged …to promote physical, mental and emotional health" (p.11) which includes addressing psychological and social needs.

As noted previously, Hampton & Newcomb (2018) found that Carers with higher levels of confidence in self-care had lower levels of perceived stress. Given this the authors suggest that greater emphasis should be placed by health-care practitioners on emphasising the importance of Carers practising self-care not least because of the importance these Carers play in providing "the caring services the [health-care] industry cannot provide for patients" (p.475). Dionne-Odom et al. (2017) suggest that enhancing self-care practices of Carers not only augments Carers' health but "resultantly their capacity to provide high-quality care to" their Caree (p. 2444). It seems as if the emphasis is on 'caring for the carer' in order that they can carry on bolstering up a creaking health care system and reduce patient admissions to hospital/hospice rather

than encouraging self-care for the sake of the Carer in and of themselves. If this is the hidden, unspoken motivation behind encouraging self-care it may offer a reason for Carers' reluctance to practise self-care (and take up the offer of supportive interventions) – Carers perceive that they are not valued as and for themselves.

Reflexive Comment: *One Carer participant of an iCare group for Carers I ran at a hospice shared that she had been told by a healthcare professional to 'look after herself' because she was important in saving the UK health service a lot of money in care costs for her Caree. Understandably she was hurt and indignant as this reinforced the message that she did not count.*

One aspect of self-care could be practising and developing self-compassion. This could fall within the ambit of Hampton and Newcombs' call for researchers to build self-care efficacy into Carer interventions. What Hampton and Newcomb (2018) fail to address are the barriers that prevent Carers from accessing supportive interventions including those fostering self-care. It has already been seen in **section 2.2.6** that there can be resistance and misgivings about becoming more self-compassionate. The arguments put forward against developing self-compassion could equally apply to self-care particularly when caring for someone who has a terminal diagnosis. Namely it is selfish, demonstrates weakness and is self-indulgent. To counter these concerns, professionals need to maintain an awareness of Carers' resistance and gently challenge these arguments.

Other barriers to self-care may be that given the amount of time Carers devote to their caring duties they are too tired, have too little time or lack motivation to participate in self-care activities. Dionne-Odom et al. (2017) suggest that "a significant proportion of caregivers simultaneously report low engagement in all forms of self-care practices" (p.2438). As this was a quantitative study it is difficult to identify the underpinning reasons for failure to engage by Carers but they suggest lack of time may in part explain this given the many hours of care provided by Carers and that Carers may feel dutybound to meet the Caree's needs rather than their own.

Could Carers be experiencing some form of stigma about accessing supportive interventions? Heath, Brenner, Lannin, and Vogel (2018) distinguish between self-stigma and public stigma (in the context of the stigma of accessing psychological help). Carers' fear of public stigma may be perpetuated if professional healthcare workers fail to endorse the importance of self-care activities in the sense that there may be concerns of 'what would others think' if e.g. I take time out for myself when my Caree is so poorly? Self-stigma which occurs "when individuals internalize perceptions of society's stigmatizing views to themselves" (Heath et al., 2018, p. 65) may play a part too in the denial of one's own needs as in some way it may be seen as admitting failure as a Carer, if you need to take time out for yourself. I was unable to locate any evidence to illuminate these ideas about carers either generally or in the palliative care field.

The concept of Carer self-care is acknowledged in both the literature and by healthcare professionals as important to encourage as part of developing Carer well-being, yet it is under-researched and appears to be resisted by Carers for several reasons.

2.8 Developing a Self-Compassion Online Intervention

Some of the technology-based psychological/psychoeducational interventions available to caregivers have been explored earlier (**section 2.6.3**). The benefits of these include cost effectiveness, ease of access, reduced travelling time for users, constant availability and the potential for personalised support, depending upon design. They also allow geographically disparate Carers to be reached. As seen in **section 2.6.3** there is some evidence to suggest that online interventions are acceptable to caregivers but have mixed outcomes and there have been calls for more research. An online self-compassion-based intervention for Carers has not been researched previously. This gap in the research together with the potential benefits that an online intervention could offer Carers encouraged the development of iCare-online, the intervention studied in Phase Two.

In relation to this study, it is useful to differentiate online learning from online self-help interventions, of which iCare-online is one of the latter. The definition provided by Cavanagh, Strauss, Forder, and Jones (2014) is helpful in this regard. They propose that

two features distinguish self-help interventions, namely that there is no or reduced input from a practitioner and that rather than provide information, self-help is about guiding and encouraging the development of skills which help users to manage their difficulties (p. 120). Consequently, literature exploring, for example, learning styles and online learning theory has not been reviewed.

Yet it is of little value introducing an online intervention if Carers do not use the internet. Recent reports indicate that internet usage is increasing across all ages (Age UK, 2016, 2020; Office for National Statistics, 2019) but those over 75 use the internet least. The average age of participants in Phase One was 58, and 65 in Phase Two. In these two age groups internet usage over a three-month period was recorded at 93% for those aged 55-64 and 83% aged 65-74. This percentage declined to 47% for those over 75 (Age UK, 2020). Based on these figures it seems likely that an online intervention may be less attractive to Carers in this latter age group. What is unknown is the impact on internet use of the lockdown during the recent Coronavirus pandemic. Ofcom (2020) reported that across all adults there was a marked increase in the time spent online, between September 2019 and April 2020, with adults spending over a quarter of their waking time online. It is not known, as of yet, how this increase is reflected in older age groups. It can be speculated that isolation and loss of contact with family and friends may have spurred an increase in internet usage as a way of keeping connected with loved ones. Consequently, this increased familiarity with technology, such as Zoom video calls, may result in a greater willingness to adopt online interventions. Whilst internet use may be increasing, an online intervention will be valueless if Carers live in remote areas with poor internet coverage or do not have the economic means to obtain up to date hardware (Demiris et al., 2019).

Building self-compassion online may be challenging and a recent feasibility study of an online five module compassion-building intervention for nurses reported high attrition rates with only 28% completing the full programme (Coster, Gould, Coulson, & Norman, 2020). This was even though this intervention, along with its ilk are designed, like iCare-online, to be flexible so as to meet participants' time commitments and busy schedules. In contrast Kubo et al. (2018) identified the acceptability of a mobile-based mindfulness

app (Headspace) for cancer patients and their caregivers. However, this was a small-scale study and the patients were not necessarily palliative.

2.8.1 Theoretical Basis

The self-compassion interventions studied in Phases One and Two (iCare/iCare-online) were developed based on the MSC programme given its usefulness in targeting self-compassion. **Section 2.2.3** has addressed the links between self-compassion and well-being including physiological benefits such as reducing the stress response and positively impacting emotion regulation when faced by stressful events, which Carers face daily. As such, iCare was developed to retain those aspects of the full MSC programme that were considered to be useful in building resources of Carers and potentially promoting self-care which could support Carers in the management of the burdens of caring.

2.9 Summary

This Chapter has identified and presented literature contextualising this research study. Literature has been examined as it pertains to the concept of self-compassion and how this may be developed. Secondly the literature review aimed to offer a greater understanding of the role and demands of being a Carer. Within the palliative care field, it was seen that there are a variety of interventions to support Carers but with mixed outcomes in terms of effectiveness in reducing distress and improving well-being. The literature review identified a gap in the literature surrounding mindfulness or self-compassion-based interventions for Carers - to date it appears that there is no research exploring a self-compassion intervention for Carers be that delivered face to face or online.

There is a paucity of qualitative literature exploring the experiences of individuals who have undertaken self-compassion training; the area is dominated by quantitative research. A further gap in the literature surrounds the lack of self-care interventions for Carers and studies exploring what self-care represents for Carers, despite there being

calls for more research. Finally, literature addressing the barriers that may prevent Carers from accessing supportive interventions was discussed.

The research methodology underpinning this research study is presented in the next Chapter.

Chapter Three: Methodology

3.1 Introduction

This chapter provides a rationale and description of the underpinning philosophy for the methodological approaches adopted in this study based upon my ontological, epistemological and methodological perspectives. The aim is to provide a clear justification for the research paradigm embraced in this study.

This study is divided into two phases. Whilst Phase Two is dependent upon the findings from Phase One, both studies stand independent of each other, although they share the same methodological position, but the methods of each study are different. In this chapter, I outline my overarching epistemological and ontological position and then I will address the method for each phase in subsequent chapters.

3.2 Philosophical Assumptions

Paradigms can be defined as a complete set of philosophical ideas or worldviews founded upon ontological, epistemological and methodological suppositions (Pitard, 2017). Historically, quantitative and qualitative methods have generally been the two modes of enquiry adopted by researchers. The positivist paradigm is usually associated with quantitative approaches. Positivists assert that there is an objective reality 'out there' that exists independently of us, and which can be known and objectively studied. Structured interviews, questionnaires and randomised controlled trials are some of the more common methods associated with this paradigm (McEvoy & Richards, 2006). Post-positivists reject this narrow definition of positivism and recognise that whilst there is an external reality, our knowledge of it cannot be perfect (Ponterotto, 2005), for example, contexts, theories, researcher values and biases can influence observations.

A relativist/interpretivist paradigm proposes that there are multiple realities and that the experience of these is influenced by culture, society or other factors, which could influence the interpretations of those realities. Qualitative approaches are usually linked with this paradigm, which places much more of an emphasis on how the world

is socially constructed and understood (Bankins, 2011; McEvoy & Richards, 2006). The philosophical approaches associated with this paradigm include phenomenology, constructionism and hermeneutics, utilising smaller scale but deep research methods such as participant observation, in-depth interviews, action research and focus groups.

3.3 Ontological and Epistemological Position

Methods adopted by researchers in constructing knowledge are based upon a set of assumptions regarding the nature of reality or being (ontology), and epistemology, that is "the way of understanding and explaining how we know what we know" Crotty (1998, p. 3). Both epistemology and ontology inform methodology and the processes involved in generating knowledge.

The process of reaching my ontological and epistemological positions was not easy and involved much reflection and wrestling with philosophical and theoretical concepts. I took comfort from the words of Silverman (2006, p. 7) who said:

> *I have lost count of the run of the mill qualitative research papers I have come across which find it necessary to define their work in terms of obscure philosophical positions…In my view, you do not need to understand these terms in order to carry out good qualitative research. Indeed, if you try to understand them, my guess is that you will not emerge from the library for many years.*

So as to emerge from 'the library' sooner rather than later and complete this thesis I eventually located an accessible, pragmatic theoretical and philosophical position that was compatible with my world views and life experience, including experience of working with Carers and hospice patients and which complemented my research.

Like many people, on a day-to-day basis I treat the objects in my world (my house, appointments, job, partner, pet, medical condition, etc) as independent, in varying degrees, from my experience, perceptions of, and theories about them. Similarly, institutions, emotions, illness, discrimination and social injustice, appear real to me,

rather than constructed by me. To illustrate this further, Maxwell (2013) gives the example of global warming: a belief that global warming is a conspiracy created by scientists for nefarious reasons will not prevent the Earth from warming. In relation to this study, I see cancer, MND, MS, dementia, as something independent of the Carer and Caree and their experience of that illness. The diagnosis through scan or biopsy of malignancy or damage to neural pathways is independent of the experience of that diagnosis. In this sense, my ontological position, that is my understanding of the nature of being or of what exists, is that of realism; there is a real world that exists separate from my knowledge and assumptions and theories about that world and that real world can only ever be imperfectly known (Maxwell, 2012).

Epistemology is the branch of philosophy that addresses the criteria for ascertaining what constitutes valid knowledge. The epistemological position adopted in this thesis is one of constructivism, contextualism and interpretivism. That is to say that there can be many valid constructions of a reality; as Maxwell proposes "our *understanding* of this world is inevitably a construction from our own perspectives and standpoints" (Maxwell, 2012, p. 5). Taking the subject-matter of this thesis then, the constructions of the causes of cancer or other life-limiting disease may be constructed, for example, as resulting from a stress response, as the result of a gene mutation or poor diet, 'God's will', karma, fate or bad luck. And the Caree and Carers' experiences and their understanding of the Caree's illness will be influenced by their individual beliefs, cultural or societal influences, gender, to name but a few of the influences on their individual constructions.

3.4 Theoretical Position

Methodology is the plan of action, design or blueprint for conducting research and governs our choices about the type of data collected and how it is analysed and which methods are utilised (Crotty, 1998; Pitard, 2017). Crotty (1998) suggests it is important to identify the theoretical perspective or "the philosophical stance informing the methodology and thus providing a context for the process and grounding its logic and criteria" (p. 3). Willig (2001) proposes that it is your epistemological stance which more directly informs methodology (rather than methods). Given my realist ontological and

constructivist epistemological position, it was important to identify both a methodological and theoretical perspective that reflected and complemented these positions.

3.4.1 Critical Realism as Theoretical Position

Critical realism (CR) captures not only my ontological and epistemological stance, but also marries with my axiological standpoint of challenging social injustice and enhancing human freedom and flourishing (Bhaskar, 1997; Maxwell, 2012). CR is a relatively new philosophical perspective that adopts assumptions from both the positivist and interpretivist paradigms (Lennox & Jurdi-Hage, 2017; McEvoy & Richards, 2006) and occupies a middle ground between these two positions of positivism and interpretivism (Mingers, 2006). The philosophical assumptions of CR originate from the work of Bhaskar (1997, 2015), the basic concepts of whom have been refined, explained and developed by several authors (e.g. Archer (1995); Danermark, Ekström, Jakobsen, and Karlsson (2002); Mingers, Mutch, and Willcocks (2013); Sayer (1992, 2000)) and have mainly been adopted in Europe. It is the less well known interpretation of CR expounded by Maxwell (an American) that has predominantly influenced this research (Maxwell, 2012). More specifically, it is his approach to combining ontological realism and epistemological constructivism and interpretivism that has fitted with my own ontological and epistemological stance, together with his explanatory clarity in deconstructing some of CR's key concepts. Maxwell uses CR in a broad sense and draws on other versions of realism that he views as compatible with the key ideas of CR: namely the singular aspect of all versions of CR is a realist ontology combined with a interpretivist epistemology (Bhaskar, 2015; Bygstad, Munkvold, & Volkoff, 2016).

Some critics have argued that CR is unworkable because of the incompatibility of the quantitative and qualitative paradigms, or who question the legitimacy of the contribution of the realist ontological position (e.g. Smith & Deemer, 2000) placing greater emphasis instead on the researcher's epistemological stance. Maxwell (2017) is adamant that there is a place for realism as it is relevant to the testing of our ideas, theories and conclusions that we draw from our data. Realism asks what data there might be that either supports or contradicts your findings and CR looks for alternative

possible theories/conclusions as part of a validity check on the researcher's explanation of the data.

Terminology used within CR can sometimes be obfuscating with authors using slightly different words to describe similar ideas. For the ease of the reader the following brief explanations of key terms are offered as these are referred to later in the thesis:

Objects/Entities - Objects (or entities) provide the basic theoretical foundations for critical realist explanations. Organisations, people, relationships and resources can all be entities (Easton, 2010). Entities will usually be structured e.g. an organisation, such as a hospice, can have departmental structures and relations between departments, and individuals within those departments who possess particular characteristics such as gender and psychological structures (Easton, 2010).

Events - can be described as "the external and visible *behaviour* of people, systems and things as they occur, or as they have happened" (Easton, 2010, p. 120). Events can be "measured empirically and are often explained through 'common sense', but these events are always mediated through the filter of human experience and interpretation" (Fletcher, 2017, p. 183).

Causal/Generative Mechanisms – can also be known as **causal structures** or **causal powers** that can trigger events. The outcome of a mechanism is contextual not linear that is, it is dependent upon other mechanisms (Bygstad & Munkvold, 2011). So there can be a contingent causality in that a mechanism may produce one outcome in one context but a different outcome in another (Bygstad & Munkvold, 2011; Danermark et al., 2002; Fletcher, 2017). Consequently, causal mechanisms are considered to be 'tendencies' or causative agents and are used to explain phenomena rather than predict them. In CR knowledge of causal powers and generative mechanisms may be based on the ability to observe their effects rather than on their direct observation (Bhaskar, 1997; Hu, 2018).

The goal of critical realist research is causal explanations not predictions of how and why events occur, that is, not to merely explain events but to look beyond to seek underlying causal mechanisms and structures (McAvoy & Butler, 2018; Wynn & Williams, 2012). In terms of answering the research question causal explanations will be sought from the data for the impact (or not) on Carers of participating in iCare either face to face or online. There is an ongoing debate about whether qualitative research and in particular that with a constructivist approach offers knowledge that may be generalised (O'Reilly & Kiyimba, 2015; Smith, 2018). In contrast CR, by accounting for mechanisms and explanations of interventions being studied can generate knowledge that can be generalised and applicable to other situations. As Potvin, Bisset, and Waltz (2010) suggest in relation to health interventions "it shifts the focus of attention to the mechanisms that generate health problems ...and the mechanisms that improve population health and well-being" (p. 439). CR offers the possibility of generalising some of the findings from this study.

3.4.2 Criticisms of CR

CR is not without its critics. It has been criticised for being 'seductive' (Brown, 2014) particularly to doctoral students (McLachlan & Garcia, 2015) because of its middle ground position between positivism and constructionism embracing as it does "an alternative ontology to that of purely social constructs (extreme social constructionism) or of purely quantitative data (extreme positivism)" (Brown, 2014, pp. 112-113). The inherent attraction in CR to some may be that the researcher gets to metaphorically 'sit on the ontological and epistemological fence', believing that CR offers the opportunity to adopt a mix and match approach to methodology without fully comprehending CR's philosophical stance. The danger then can be that CR is applied in a perfunctory and/or misleading manner. It is hoped that through transparency of descriptions of data collection and analysis together with a detailed exploration of the findings from this study this criticism will be rebutted in this thesis.

Positivists allege that CR's axiological stance of emphasizing human freedom and flourishing (Collier, 1994) results in bias as judgement is called for when applying values (Hammersley, 2009). It can be argued that all research (both quantitative and

qualitative) is influenced by values whether these are acknowledged or not and critical realists would assert that in making any judgement it is important to be as informed as possible, hence the significance of identifying generative mechanisms (Walsh & Evans, 2014). Further, these criticisms can be countered by the specific nature of CR analysis in that the researcher needs to account for the varying mechanisms in play within the data including the researcher's own impact on the intervention being researched. This can include how the researcher's presence and actions bring about other causal mechanisms.

Denzin and Lincoln (2011) reject CR outright, claiming the social sciences have no place for CR given what they considered CR's ambiguous commitment to "issues of social justice, equity, nonviolence, peace, and universal human rights" (p. 11), in that this remains a choice rather than an imperative of the CR approach. Indeed, by the 5th edition of their edited book (2018) they make no reference to CR, presumably as they consider CR no longer pertinent to qualitative research. Yet there are a number of examples of CR informed qualitative research including those with a transparent commitment to, inter alia, social justice (e.g. Aquino, Olander, & Bryar, 2018; Davey, Clarke, & Jenkinson, 2018; Patel & Pilgrim, 2018; Terry & Braun, 2016).

However, a limitation of CR is that there has been a concentration on theoretical work with less empirical work, given the lack of systematic methods of data analysis (Sims-Schouten, Riley, & Willig, 2007). Recently there have been other researchers who have focussed on clarifying procedural steps in CR analysis (e.g.Bygstad & Munkvold, 2011; Bygstad et al., 2016; Fletcher, 2017; Lennox & Jurdi-Hage, 2017; McAvoy & Butler, 2018; Parr, 2015), whilst Danermark et al. (2002) set out a six stage model for conducting a CR analysis. Going forward more empirically driven literature may be forthcoming which will help to counter this argument. Chapters Four and Seven identify how qualitative data analysis was conducted within a CR framework and Chapter Eight identifies a causal mechanism within the data.

3.5 Methodological Position

This study has a number of research aims, which include exploring Carers' experiences of learning self-compassion on-line in a brief format, exploring the impact this has on Carers in terms of well-being and potentially identifying any causal explanations that might account for any changes in self-compassion. Much of the research in the arena of caring for those with life-limiting and palliative diagnoses is quantitative and whilst this may be useful, if not necessary, for policy makers and funders/providers of services (often charities, in the palliative field) perhaps some caution should be introduced. Carers offer prolonged care over many months and years but ultimately, they and their Caree move into an 'end stage' of caring as the Caree's health declines and nears death. It is likely that Carers' mental and emotional well-being (as well as physical well-being) is also likely to decline as the reality of the impending death looms large. Whilst quantitative data may capture snapshots of well-being (generally on a self-report basis) the quantitative data is unlikely to ever fully capture the richness and nuances of Carers' experiences. Chapter Two also highlighted the preponderance of quantitative research in the mindfulness and self-compassion field with limited qualitative research exploring the experience of participants in self-compassion training.

The dominance of quantitative research in the study subject area could suggest that a methodology based on phenomenology that focused on Carers' lived experiences of participating in iCare/i-Care-online could have been an appropriate methodology for this study. Yet phenomenological methodologies such as interpretive phenomenological analysis (IPA) were not selected. Whilst I am interested in the phenomenological aspect of the participants' accounts of iCare, I was looking wider than the idiographic experience in order to identify and focus more on patterned meaning across the dataset. Additionally, CR is less compatible with IPA as IPA foregrounds the phenomenological, idiographic and interpretivist paradigm only, not seeking to identify causal mechanisms.

Grounded theory (GT) was a further methodology initially considered and, whilst it can be argued that GT could be used within a variety of theoretical perspectives and lends itself to CR (see Oliver, 2011), it has been criticised by some critical realists for its focus

on empiricism, a rigidity in application and the foregrounding of induction (Danermark et al., 2002). A full GT study aims to develop a substantive theory from the data, which was not a goal of this research.

After consideration, mixed methods was the methodology adopted in this study. CR's epistemological and ontological framework allows for combining relativist qualitative methods with realist quantitative methods (Harper, 2012). Mingers (2006) concurs asserting that CR permits a multimethodological approach as it is pluralist both in terms of ontology and epistemology. As described earlier, CR recognizes the existence of an array of entities be they "material objects and forces, social structures and practices, conceptual systems such as languages, beliefs and reasons, and feelings and experiences" (Mingers, 2006, pp. 214-215). These may not be observed or perceived but are considered real, due to their causal effects. From a CR epistemological standpoint, the means of assessing them will be different as physical objects can be measured and observed (quantitative analysis) whereas qualitative investigation (including participant perspective) lends itself to examining social norms and practices. Additionally a hermeneutic analysis may be required for personal values and emotions (Mingers, 2006). This maps onto the data collection and analytical approach adopted in both phases of this study, namely the utilisation of quantitative instruments together with interviews, participant online comments and qualitative questionnaire data thematically analysed through an interpretive lens. Together this data, it was anticipated, would provide for the possible explanation of causal mechanisms.

Braun and Clarke (2013, p. 333) state that "qualitative research within mixed methods approach is rarely *Big Q qualitative research*". *Big Q research* is qualitative research carried out within a qualitative paradigm seeking to deeply engage with the data to gain insights into how participants, for example, experience the world. This can be contrasted with *small q research* which utilises qualitative methods within a predominantly quantitative/positivist paradigm where data is analysed using a hypothetico-deductive research design (Kidder & Fine, 1987; Willig, 2013). Contrary to this assertion, this study foregrounds the qualitative research undertaken; data has been

collected and analysed within a post-positivist paradigm rather than a positivist paradigm.

3.5.1 Mixed Methods Methodology

Mixed methods methodology originated from the late 1980s and early 1990s. There has been increasing interest in mixed methods and pluralistic research, combining quantitative and qualitative methods (Barker & Pistrang, 2005; Barker, Pistrang, & Elliott, 2016; Creswell & Creswell, 2018; Leech & Onwuegbuzie, 2011). A mixed methods approach aims to draw upon the strengths of both quantitative and qualitative methods and minimise the weaknesses inherent in each (Johnson & Onwuegbuzie, 2004). Creswell and Creswell (2018) define mixed methods research as "an approach to inquiry involving collecting both quantitative and qualitative data, integrating the two forms of data, and using distinct designs that may involve philosophical assumptions and theoretical frameworks" (p. 4). Whilst this study is predominantly qualitative, by using two self-report measures a quantitative element is introduced and it thus falls within the above definition of mixed methods research. To fully meet Creswell et. al's definition it is important to identify a design and theoretical framework that will accommodate both CR and a mixed methods approach.

Greene, Caracelli, and Graham (1989) propose five main *purposes* for adopting a mixed method approach namely:

- *Triangulation* (to corroborate results and eliminate any biases in only one method)

- *Complementarity* (to enhance and clarify results from one method with results from another)

- *Development* (to use results from one method to develop another method)

- *Initiation* (to uncover contradictions and new perspectives)

- *Expansion* (to increase the breadth and range of findings)

The research design adopted in this study aims to prioritise the qualitative data with the quantitative data further enhancing and illustrating the qualitative data (the Complementarity purpose).

Additionally Creswell and Creswell (2018) identify three core mixed methods *designs*: the *convergent* design (quantitative and qualitative data are collected, analysed separately and results compared); the *explanatory sequential* design (quantitative data is collected analysed and the results used to plan the second qualitative phase); and the *exploratory sequential* design (qualitative data is collected, analysed and used to develop the quantitative phase). This is in line with Creswell and Plano Clark (2017) who reflect on the development and evolution of their typology of mixed methods designs. From seven types of design including a convergent parallel design (incorporating what was previously known as concurrent triangulation) and an embedded design (originally named as a concurrent nested design), they have now reduced the typology of mixed methods designs to three core designs in line with Creswell and Creswell (2018) outlined above. Creswell and Plano Clark (2017) explain that their intention was to focus on what outcome the researcher hopes to gain by mixing two methods. Rather than focus on triangulation of data, the emphasis is placed on what the researcher does with the data – in this study to heighten understanding by converging both quantitative and qualitative data.

Creswell and Creswell (2018) state that in a convergent design the quantitative (or qualitative) data is being used to "confirm or disconfirm" the qualitative (or quantitative) data. This is somewhat contradicted by Creswell and Plano Clark (2017) who propose that rather than confirming or contradicting data, the essence of a convergent design is to compare the results obtained from the different data sources in order to reach a fuller understanding of the research topic. This is in line with the Danermark et al. (2002) third purpose for mixing methods – using "quantitative and qualitative methods side by side in order to empirically elucidate a phenomenon in as

much detail and as thoroughly as possible" (p. 153).This is encompassed by the complementarity model of triangulation described by Langdridge and Hagger-Johnson (2009) in which "two methods are used to complement each other" (p. 484).

Under earlier typologies it could be argued that the current study adopts an embedded (or nested) design given that there is a focus on the qualitative method with the quantitative method embedded within the overall design. Alternatively, it could be considered that a triangulation design has been used. However, reflecting the move away from these design typologies (Creswell & Creswell, 2018; Creswell & Plano Clark, 2017), the most appropriate design is a convergent mixed methods design, adopted on the basis of its compatibility with CR (McAvoy & Butler, 2018) and for the Complementarity purpose (Greene et al., 1989); in order to answer this study's research question the underlying model supporting the mixed methods methodology is a convergent design based on complementarity (Langdridge & Hagger-Johnson, 2009) with the aim of illuminating the phenomenon of Carer self-compassion as thoroughly as possible (Danermark et al., 2002).

3.6 The Practical Application of CR

CR involves an ontological and epistemological position suited to researching people in their social/health context (Walsh & Evans, 2014), which seems appropriate for researching Carers and a self-compassion intervention. Potvin et al. (2010) consider that CR is particularly suited to exploring health interventions as it centres attention on identifying mechanisms that cause health problems or on mechanisms that enhance health and well-being. The way of applying a critical realist analysis to data is less clear, as referred to above.

CR has been the subject of criticism for its lack of guidance on methodology, (Fletcher, 2017; Hu, 2018; McAvoy & Butler, 2018; Sims-Schouten et al., 2007). Danermark et al. (2002) do set out a six-stage explanatory model of CR. They stress that their model is a guideline and not a template to be unquestionably followed, encouraging research processes to be structured in a variety of ways (see Lennox and Jurdi-Hage (2017) for an adaption of this model in their research into street harassment). Similarly Maxwell

(2012, 2013) is not prescriptive about how to conduct data analysis rather his focus is on identifying causal mechanisms and processes and exploring validity threats to any explanation for the findings arrived at. Although within a CR framework there is relative freedom in conducting data analysis, to ensure rigour, a well-established method for qualitative data analysis was adopted (Braun & Clarke, 2006) which was also compatible with CR's philosophical position (this method of data analysis is further explored in Chapter Four). Chapter Eight offers a causal mechanism based on the findings of Phases One and Two.

One further consideration in applying a critical realist approach is when to conduct the literature review as there is some debate as to whether a priori theory should or should not be part of retroduction (McAvoy & Butler, 2018). Hu (2018) defines retroduction as the step in analysis where the researcher hypothesises "about the causal powers, mechanisms or structures that possibly generate the focal social event" (p. 125). Hu (2018) considers existing theories to be part of retroduction and this is certainly the position adopted by some researchers (Fletcher, 2017; Lennox & Jurdi-Hage, 2017).Whilst in this study my prior knowledge of certain key theoretical concepts will have had some influence on the qualitative analysis a decision was taken to undertake retroduction after the literature review had been carried out which is in line with Hu's guidelines to conducting critical realist informed research and which seemed logical to aid the development of explanations for causal mechanisms.

3.7 Ethical Considerations

Mixed methods researchers have been shown to pay scant attention to ethical considerations and reflexivity in their published work (Cain, MacDonald, Coker, Velasco, & West, 2019). To demonstrate high-quality, credible methodological practice and counter this prevailing praxis there follows a full description of ethical considerations and reflexivity. Both phases of the study were reviewed and granted separate ethical approval by the Ethics Committee of the Department of Social & Political Science, University of Chester (see Appendix 2). The research was informed by the ethical and research frameworks and guidelines of the British Association for Counselling and Psychotherapy applicable at the time of each study (2017a, 2017b, 2018a,

2018b) together with the British Psychological Society (2017) Ethics Guidelines for Internet-mediated Research.

The following ethical considerations were attended to prior to commencing the research study.

3.7.1 Informed Consent

Informed consent aims to empower potential participants to make decisions that are in their own self-interest by providing information about all aspects of the research including what participants' involvement in the research will be and what happens to the data after their involvement has finished (O'Reilly & Kiyimba, 2015).

Potential participants in both phases of the study were given opportunities to ask questions about the research. Given that the research involved participants undertaking a 'training' course in self-compassion, which encouraged them to listen to recordings and practise in their own time, before either being interviewed (Phase One), or completing an online questionnaire (Phase Two), it was important that this aspect of the study was explored fully before participants decided to participate. Participants were then given or emailed a copy of the participant information sheet (see Appendices 4 and 12). Potential advantages and disadvantages of taking part in the study were explained to participants.

In Phase One, a consent form was discussed with each participant before they were asked to sign it; in Phase Two the online questionnaire site was so designed that participants had to confirm that they had read the participant information sheet before completing the online consent form (see Chapters Four and Six for further details). Participants were reminded that they could withdraw from the study at any time but their participation in iCare/iCare-online would not be affected. Consent was re-visited as a few participants offered thoughts or comments via email after the formal data collection had been completed and it was felt important to seek their approval to include their comments in any analysis, echoing the endorsement of O'Reilly, Parker, and Hutchby (2011) that consent is an iterative process. Copies of transcripts of the

interviews in Phase One were sent to participants for their comments to ensure that they were comfortable with what they had said in the interview. In Phase Two participants typed up their comments so could see what they were disclosing before forwarding to me and they continued to have access to a copy of what they had sent via iCare-online or in their personal email system.

3.7.2 Confidentiality and Anonymity

Participants were informed about the management of their private information including:

- In Phase One – that all participants' identities would be anonymised using a pseudonym; that any identifying data would be removed including the geographical context of the delivery of the programme and that data would be encrypted and any physical material including that containing personally identifiable data would be kept in locked cabinets.

- In Phase Two – that data provided online (such as brief biographical data, completed outcome measures, communications about their experience of iCare-online and the final questionnaire) was held on two platforms Online Surveys (/www.onlinesurveys.ac.uk/) and through a web site hosted by www.Wix.com. When using the Online Surveys platform participants were given a username/password combination and a personalised URL for data collection purposes. Both platforms were hosted on secure, encrypted servers and had privacy policies, details of how to access these were given. Participants were also advised that there was a limit to confidentiality given that I did not control Online Surveys and www.wix.com. As in Phase One all participants' identities were anonymised using a pseudonym.

- For both Phases - that in accordance with the University of Chester's Research Governance Handbook, data generated in the course of the research will be kept securely in paper or electronic format for a minimum of ten years from the date of final publication and kept in accordance with the Data Protection Act 2018.

3.7.3 Risk of Harm

Both participant and researcher can face possible risk of harm which needs to be considered when developing research. An assessment of the potential gains for participants needs to be weighed against any possible distress that participants could face (Hammersley & Triaianou, 2012). In this study potential benefits included the opportunity to learn new skills and practices with the aim of building resilience and managing stress. As participants developed mindfulness and a more self-compassionate orientation, there was the possibility that through greater awareness of the challenges of the caring situation and their own physical, emotional and psychological state this could result in some painful and emotional difficulties. The structure of iCare both in the face to face version and online was created to be supportive with facilitator support designed to address any potential difficulties participants experienced as they emerged. Previous experience of teaching mindfulness and self-compassion to Carers and Carees indicated that extreme overwhelm was very unlikely particularly as iCare is a resource building intervention and participants were taught skills in managing strong emotions. However, one or two participants in both phases did experience strong emotions when practising meditations/exercises or in daily life as they opened to the impact of caring. They were offered support and guidance including suggestions to withdraw from the study if they felt participation was too distressing, but all proceeded with the study.

Harm can also be experienced by participants in research interviews when an exploration of the subject area solicits painful emotional responses (Ahern, 2012). During the face to face research interviews of Phase One some participants did experience a few emotional moments, but these appeared to be related to the poignancy of becoming more self-compassionate rather than acute distress. One participant was particularly upset as she recounted the positive but powerful impact of one practice. She was asked if she would like to end the interview, but she chose to continue.

A further ethical concern arose when one participant in Phase Two was sent a reminder through Jisc (2019) encouraging completion of the online survey and outcome measures. She immediately completed the survey and measures but sent a separate email apologising for the delay and explained that her husband had died in the hospice nine

days or so before. Condolences were quickly expressed; from the content of her email it was clear that she had found participation in the research valuable and wanted the research to impact other Carers. She did not appear to find the email reminder distressing although I felt uncomfortable that she had not only been contacted but had chosen to complete the survey at such a painful and difficult time.

The risk of harm is not only limited to participants but can involve the researcher. Being both facilitator and researcher, I was involved with participants for varying periods of time and in most cases developed a close relationship with participants. As O'Reilly and Kiyimba (2015) point out, such close relationships are often part of qualitative research but they increase the chance of emotional impact through exposure to the content of participants' narratives. Throughout the study I had access to support from my academic supervisor, my counselling supervisor and I also sought support from an experienced teacher of mindfulness and the MSC programme. However, I was affected by participants' experiences and exposure to the realities and pain of caring as a Carer and this is explored further in **section 3.9** and Chapter Nine.

3.7.4 Beneficial Consequences

The method utilised to analyse the qualitative data, reflexive thematic analysis, (see Chapter Four for a detailed exploration of this method) can be used to generate accessible knowledge capable of straightforward communication. Following a social justice imperative and as a practitioner-researcher I consider it ethical that there is a possibility of this research generating beneficial outcomes for participants (Brinkmann & Kvale, 2017). Additionally the participants' generosity and willingness to make a commitment to exploring iCare/iCare-online and give up more of their valuable time to participate in interviews or answering questionnaires ought, if possible, to be reflected in the generation of data that may have the potential to influence Carer service provision.

3.7.5 Power and Positionality

Throughout both phases of the study, I acted as facilitator of iCare/i-Care-online and also as researcher. Participants knew that I was a counsellor in a hospice, a teacher of

mindfulness and self-compassion as well as a researcher. In terms of the ethical considerations of this, my professional background is very likely to have impacted the participants, in particular their perception of me as an 'expert'. I made efforts to avoid as far as possible 'doing expert' (Braun & Clarke, 2013) throughout the research process but at times it was hard to avoid 'doing teacher' when participants looked to me for guidance as they learnt new skills. Whilst I aimed for a balance of power between myself as researcher and the participants it is generally assumed that it is the researcher that holds the power (O'Reilly & Kiyimba, 2015) and as such I endeavoured to maintain awareness of not intimidating or forcing participants (Orb, Eisenhauer, & Wynaden, 2001).

Positionality involves acknowledging the relationship between researcher and researched (Jacobson & Mustafa, 2019; O'Reilly & Kiyimba, 2015); understanding our own social identities in comparison to the social position of participants will also assist in exploring the power relations permeating our research (Jacobson & Mustafa, 2019). As such I attempted to be mindful of the language I used, especially when explaining concepts that I was familiar with, but which were alien to my participants.

A further important ethical consideration is the closeness and rapport that I developed with participants across both phases of the study and the possibility that I was '"Doing rapport' … 'faking friendship'"(Duncombe & Jessop, 2012, p. 108), which could potentially be misleading participants about a friendship that did not in fact exist. My background as a counsellor undoubtedly means that I used counselling skills as part of both my facilitation of the face to face version of iCare, within responses to email feedback in iCare-online and during the qualitative interviews, the use of which Duncombe and Jessop (2012) suggest is part of the technique for 'doing rapport'. I considered that I was ethical and authentic throughout the research and had no sense that I was 'doing rapport' and certainly in the findings from both phases (Chapters Five and Seven) participants make mention of my authenticity. Rather the intimacy between myself and participant seemed to develop through the self-intimacy that participants discovered through iCare/iCare-online and which fostered mutuality something which Sinding and Aronson (2003) consider may not be in the best interests of participants, but not

something in this instance that I concur with. Rather, mutuality promoted a sense of both participants and myself as equals in both the intervention and the research process (Newton & Parfitt, 2011).

3.8 Quality in Qualitative Research

A further ethical consideration is to what extent research is deemed to be of 'good quality'. Issues of quality assessment in qualitative research have been the subject of debate for some time but a consensus has yet to be reached on how qualitative research should best be critically appraised or indeed if any evaluative criteria are needed at all given the different philosophical underpinnings of quantitative and qualitative research (O'Reilly & Kiyimba, 2015). There has been dissatisfaction with applying quantitative principles such as reliability, generalisabilty, validity or objectivity to qualitative research (e.g. Willig, 2013) (although within a CR framework a form of generalisability is favoured). As the debate and literature is extensive and wide ranging the limits of this thesis do not allow for a full exploration of the subject area. Instead the focus will be on establishing how matters of quality have been addressed in this study and the reasons for the selection of the chosen evaluative criteria.

As this is a predominantly qualitative study with limited descriptive quantitative statistics, I have focused on establishing the guiding principles for evaluating quality adopted in the qualitative aspects of the study. Heeding the advice of O'Reilly and Kiyimba (2015) and Braun and Clarke (2013), I set out below my explication and justification for the quality markers adopted.

Braun and Clarke (2013) suggest that triangulation and member checking may be suitable techniques for establishing the quality of qualitative research (albeit that these techniques are considered controversial). Triangulation is a process "whereby two or more methods of data collection or sources of data are used to examine the same phenomenon, with the aim of getting as close to the 'truth' of the object of study as possible" (p. 285). In this study through adopting a mixed-methods approach I am using triangulation (interviews, qualitative questionnaire and outcome measures); this fits with a realist qualitative study, although I do not accept a 'single knowable truth' but

rather a 'single *unknowable* truth'. I see triangulation in this instance as getting to a richer and more nuanced picture rather than an accurate account of *'the truth'*.

I dismissed the use of member checking my analysis with participants. For practical reasons it felt too onerous a requirement to be placed on already over-stretched Carers; it would be unfair to expect them to devote more time to consider my analysis. As the analyses were conducted many months after data collection, contact with participants could have been at a time when their Caree was not only very poorly but could have died and member checking would have added to their distress. Whilst ontologically member checking fits with a realist framework of identifying a 'truth' of say the participant's experiences, as I have adopted a critical realist approach involving a more subjective interpretive analysis:

> *'there is no reason why non-academic participants should be especially qualified to validate it'* (Taylor, 2001: 322). *The participants' approval cannot 'prove' or 'disprove' the analysis, because it is not intended as a reflection of their experience as they understand it* (Braun & Clarke, 2013, p. 285)

In completing the thematic analysis (TA) of the qualitative data (see Chapter Four) the 15-point checklist of criteria for a good TA, as set out by Braun and Clarke (2006), was followed. Mid-way through 2020 Braun and Clarke published a paper commenting on quality practice in TA (2020). This highlighted ten common problems which can arise in published TA research. This prompted a critical review both of the analyses of the qualitative data and the content of chapters Four, Five, Six and Seven to ensure the study did not exhibit any of the ten problems highlighted. This resulted in further reflection of the position I had adopted as a researcher together with brief revisions to the thesis. I considered it important to clarify:

- the version of TA being adopted in this study and the versions of TA which were not selected and the reasons for that decision

- that TA in this study is being used as an experiential/contextualist method

- that themes identified in the analyses were united by a central organising concept based on shared meaning and not merely topic summaries

Validity has been rejected by many qualitative researchers as it is seen as too intrinsically connected to a positivist understanding of research (Maxwell, 2013, 2017; Willig, 2013). Maxwell (2013) uses 'validity' in what he calls a common-sense way "to refer to the correctness or credibility of a description, conclusion, explanation, interpretation, or other sort of account" (p. 122). In seeking validity in qualitative research he proposes that it is necessary to ask what other possible alternative explanations there might be that do a better job at explaining your analytic conclusions (Maxwell, 2017). He refers to 'validity threats' as essentially alternative possible explanations for your findings but makes mention of 'bias' and 'reactivity' as two specific validity threats (Maxwell, 2013). It is not possible to eliminate researcher bias (e.g. my theories, beliefs, values) but I need to account for *how* this may have impacted the study. In terms of reactivity or what is better known in the qualitative research world, reflexivity, the influence I may have on participants through e.g. the iCare intervention (both face to face or online) and the interview is inescapable but, as for bias, needs to be accounted for by understanding how this may influence the participants and to what degree this affects any inferences I draw (see **section 3.9** below for further exploration).

Finally, several authors have identified various lists of quality criteria that can be applied to qualitative research, but space precludes a detailed account of these. In line with Sparkes and Smith's (2013) suggestion that criteria can be adopted in a mix and match approach as long as there is a coherent rationale for doing so, I have selected a number of criteria from lists which I consider to be relevant to this research. Namely from Tracy's eight 'big-tent' criteria (2010) I consider that the subject matter of this thesis is a *worthy topic* of research as it is relevant to the lives of many Carers today and could be significant to health care providers; the research does demonstrate *sincerity* I believe, in that I attempt to be self-reflexive as a researcher and fully transparent about my research methods and any challenges encountered. *Credibility* is achieved by full, detailed and thick descriptions of the findings and the use of triangulation; as

demonstrated above the research is *ethical* in that a variety of procedural, situational and relational ethics have been considered; and the research has *meaningful coherence* in that I consider that the methods and procedures fit with the aims for this study and that useful interconnections between the literature, findings and my interpretations have been made (although the reader will make their own judgements of this). Within what Tracy identifies as *Resonance* is the idea of *transferability,* a quality marker adopted by a number of qualitative researchers (Braun & Clarke, 2013; Nowell, Norris, White, & Moules, 2017; Smith, 2018). Transferability will be achieved if other types of carers, professional or informal, therapists or compassion-based teachers see that this research might overlap "with their own situation and/or they can intuitively transfer the findings to their own action" (Smith, 2018, p. 141).

From Yardley's (2000) four broad, flexible principles for appraising the quality of qualitative research I am including *impact and importance* as a final criterion. I view this study as having practical impact for not only those working with Carers but also those teaching self-compassion more widely or using it in a therapeutic capacity with others. The findings may help to elucidate ways of providing support to Carers and carers more generally and in keeping with the social justice agenda of CR and reflexive TA (Braun & Clarke, 2019b) may add to the calls for social change and recognition for Carers, an often invisible group.

3.9 Reflexivity

To add to the credibility, trustworthiness and rigour of this research study, it is important that I explicate my position and lens through which the process of the research has been conducted. This is in keeping with addressing Maxwell's critical realist position and naming of specific validity threats to qualitative research (Maxwell, 2013, 2017) i.e. researcher bias and reactivity (the influence of the researcher on participants). I attempt to meet his requirement of qualitative research, namely that I identify:

> *how a particular researcher's values and expectations may have influenced the conduct and conclusions of the study …and avoiding the negative consequences of these* (Maxwell, 2013, p. 124)

In doing this I strive to adopt both a reflexive position exercising a "thoughtful, conscious self-awareness…encompass[ing] continual evaluation of subjective responses, intersubjective dynamics, and the research process itself" (Finlay, 2002, p. 532) together with what West (2011) describes as a "critical reflexive subjectivity" (p. 44). As part of this process I maintained research journals to capture insights, thoughts, feelings and reaction to the research journey, my participants, the data collected, the process of the analysis and ultimately the conclusions that I drew from the data.

Reflexivity plays an essential part in controlling the quality of qualitative research (Braun & Clarke, 2013) and can be differentiated between a functional reflexivity and a personal reflexivity (Wilkinson, 1988).

3.9.1 Functional Reflexivity

Functional reflexivity involves critically addressing "the way our research tools and process may have influenced the research" (Braun & Clarke, 2013, p. 37). In relation to this study data was collected via interviews in Phase One and via module feedback and qualitative questionnaire in Phase Two. In the former, as researcher, I was very much present which may have impacted on participant disclosures with participants less likely to share what they considered negative comments about iCare. In the latter as a more remote presence this may have facilitated more open comments. Alternatively, data collected may have been different if in Phase Two rather than using questionnaires, interviews were held online. In either case though, unlike say focus groups, participants were not affected by what other participants felt about iCare/iCare-online.

3.9.2 Personal Reflexivity

Personal reflexivity involves reflecting on the ways in which the researcher with their values, views, experiences, attitudes, assumptions has shaped the research. In Chapter One I outlined my positioning in the research. Additionally, I also explored my personal

reflexivity through the adoption of 'I' positions which I now explain. There are numerous articles and books which explore reflexivity and outline suggestions as to how this may be achieved, but the article written by Bradbury-Jones (2007) captured my attention and it is the suggestions she makes of using Peshkin's (1988) approach of identifying your subjective 'I' which may influence your research that I have predominantly followed. Peshkin proposes that your subjectivity takes the form of several 'I' positions that may have distinct characteristics such as his 'Justice-Seeking I' or Bradbury-Jones' 'The Maverick I'. I want to stress that by searching for and illuminating my 'I's, I was not intending to provide a narcissistic, self-indulgent account of my research journey but rather to provide a multi-faceted narrative of my subjectivity which illuminates how becoming a reflexive researcher impacted this research (Etherington, 2004, p. 31). I am attempting to "strike a balance, striving for enhanced self-awareness but eschewing navel gazing" (Finlay, 2002, p. 541).

I systematically analysed two research journals, one which I started when I began my PhD journey at another university and the second which I used when I restarted my PhD and became a doctoral student at the University of Chester. It felt valuable to capture entries made in the first journal because at that time I was also a Carer of my mother and the insights I gained from this experience undoubtedly influenced the research and framed my approach to this study. The journals were read and re-read, and pertinent entries highlighted. These entries were then transferred into a word document and initial comments made on the data extracts and, mirroring some of the steps of a thematic analysis, initial codes developed before clustering codes not into themes but 'I' positions. This proved to be an uncomfortable and at times painful experience but a valuable and fruitful exploration which I consider adds to the credibility of my research. I identified several 'I' positions and discuss the ramifications these had for the study (Bradbury-Jones, 2007) in Chapter Nine.

3.10 Summary

This chapter considered my epistemological and ontological positions as researcher and explored the philosophical foundations underpinning CR. The methodological approach of mixed methods used to conduct the research was discussed. In addition,

the ethical considerations of the study were also reviewed together with an exploration of quality criteria and reflexivity.

Chapters Four and Six will outline the Research Design of both phases of the study including data collection and analysis describing how a Mixed Methods Methodology was applied in practice.

Chapter Four:
Research Design and Method - Phase One

4.1 Introduction

Phase One of this study incorporated a predominantly qualitative mixed methods study comprising a reflexive TA (see **section 4.7.1**) of semi-structured interviews with nine participants in a one-to-one face-to-face delivery of a brief, four session mindfulness and self-compassion programme for Carers (iCare). Additionally, outcome measures were completed prior to commencing iCare and after completion of iCare. Phase One focusses on participants' experiences of participating in iCare and learning mindfulness and self-compassion approaches and meditations as well as assessing changes in self-compassion and psychological functioning of participants through self-report outcome measures. It was intended that the findings from Phase One would provide a theoretical and pragmatic justification for the content and structure of the online version of iCare to be studied in Phase Two.

4.2 Recruitment and Procedure

The study was advertised using advertisements/posters (See Appendix 3) displayed in Carer organisations, health charities and hospices in the North West of England. Copies of participant information Sheets (see Appendix 4) were made available at these sites for potential participants to read. In addition, the study was also advertised using Twitter, LinkedIn, email and on the home page of my website (Diggory, 2017). Nine participants were recruited.

- A pinned Tweet was used on my Twitter account @iCareResearch (see Appendix 5) advertising the research and carer organisations in the North West of England were also sent direct messages via Twitter regarding the research.

- LinkedIn recruitment comprised an update describing Phase One of the study and posted on my profile.

- Email recruitment was through an email which outlined the study and contained the participant information sheet and research poster. This was forwarded to all contacts and re-forwarded by others, to their contacts.

The main research criteria were that participants must be aged 18 or over and caring for an adult with a life-limiting or palliative diagnosis who were sufficiently fluent in English to understand the material being delivered and able to participate in an interview. It was hoped that whilst participants would of necessity have to be homogenous in the sense of their caring responsibilities, they would be representative of the diversity of Carers regarding gender, sexual orientation, cultural background and age.

Participants were predominantly recruited directly from hospices (six), as a result of email recruitment (two) and in response to details of the research placed on my web site (one). Recruitment was carried out over a three-month period. A pragmatic approach to sample size was adopted (Braun & Clarke, 2016, 2019c). Recruitment ceased after nine participants were identified. Consideration was given to the amount of data that nine interviews would generate but also recognising that each participant would require the delivery of four sessions of face to face iCare; a minimum of 36 hours of my time plus time for interviews could be accommodated within the project plan but more than this would have been too time-consuming.

Interested participants contacted me using email or mobile telephone for further information. Following this initial contact if they had not previously seen a participant information sheet one was sent to potential participants. Once a participant had made a decision to participate in Phase One of the study, they signed the consent form (see Appendix 6) and completed paper versions of the pre-iCare quantitative outcome measures before arrangements were made for the face to face sessions of iCare.

Approximately two weeks after participants completed the iCare programme they then completed the follow-up outcome measures and participated in a face-to-face semi-structured interview with me which lasted between 31 and 59 minutes, with one

participant adding further comments by email. These took place at locations to suit the participants which included their local hospice, their home or my home office. The interviews were recorded using a digital voice recorder. Interviews were transcribed based upon orthographic transcription (Braun & Clarke, 2013). Participants were allocated pseudonyms to preserve anonymity. Participants received a copy of the transcript of their interview for them to review and make any amendments.

4.3 Development of Interview Guide

An interview schedule was developed guided by Agee (2009) and refined following discussions with my supervisor. This was then used as a guide to conduct the semi-structured interviews. Such interviews allow for the same topics to be discussed which does allow for some comparability of data. They also allow participants freedom in raising particular matters of interest or concern to them (Rubin, 2012). As I was seeking to understand the participants' experience of the iCare programme, including their perceptions of its feasibility, and capture their thoughts about moving it online, questions were framed to reflect this. The interview guide was not rigidly adhered to but used as a guide, allowing the participants to share understandings and experiences that seemed most pertinent to them. Follow up questions were asked spontaneously with the aim of exploring areas more fully (Braun & Clarke, 2013; Opperman, Braun, Clarke, & Rogers, 2014) which added to the depth and authenticity of the data. A copy of the interview guide can be found at Appendix 7.

Of importance was the development of a warm and trusting relationship with participants to glean the best quality data possible. As Ryan and Dundon (2008) suggest:

> *In order to encourage positive engagement of the highest form there is a simple rule of thumb: the better the quality of the relationship between interviewer and interviewee, the richer the quality of the data elicited. This is because experience shows that when interviewees are comfortable and trusting, they relate richer stories and elaborated explanations* (pp. 443-444)

I had the advantage of working with participants over a sustained period such that at the time of the interview we had developed a good rapport with one another whilst also striving to maintain my position as researcher. The ethical considerations of the dual role I held as facilitator of iCare and researcher were consistently borne in mind (Fleet, Burton, Reeves, & DasGupta, 2016) and whilst researching professional practice can be elusive (Billington, 2018) the opportunity offered by this insider perspective was considered to be valuable (Fleet et al., 2016).

4.4 Participant Biographical Data

Participants' ages ranged from 38-78 (mean age 58) and were all White females, some in employment, others retired or given up work to care for their Caree. Carees were diagnosed with a variety of illnesses:

- Parkinson's Disease & Multiple System Atrophy (1)
- Cancer (3)
- Motor Neurone Disease (2)
- Cerebral vascular disease/dementia (2)
- Spinocerebellar Ataxia (1)

The relationship between Carer and Caree was that of spouse (5), daughter/parent (3) and friend (1). Further biographical details can be found in Chapter Five.

4.5 Intervention – iCare

4.5.1 Theoretical Basis for iCare

The self-compassion intervention studied in Part One was iCare. It is based on the MSC programme adapted to reflect the needs of Carers. Chapter Two, **section 2.8.1** provides further details of the basis of iCare.

4.5.2 iCare Development

iCare comprised four modules delivered on an individual basis, face-to-face, over four weeks by myself as facilitator. In designing iCare the intention was to develop mindfulness as a foundational skill in participants before moving on to introduce self-

compassion and target the challenges and needs of Carers. Hence Module One introduced the concepts of mindfulness and self-compassion but focused primarily on developing mindfulness skills; Module Two introduced self-compassion concepts and the development of a self-compassionate orientation in Carers in the face of their challenges; Module Three focused more particularly on Carer challenges with particular emphasis on Carer fatigue; Module Four continued to develop self-compassion practices and introduced a gratitude practice as well as identifying further resources to support participants following completion of the intervention. Each module lasted about one hour in duration with the facilitator guiding practices and meditations, offering brief theoretical explanations and supporting the participants in their practice and day to day experience of iCare.

Supporting material was offered by way of two CDs with recordings of meditations and practices together with handouts summarising the key points from each session. Table 2 below details the content of iCare in its face to face Phase One format.

Table 2 *Content of iCare Intervention-Phase One*

	Session 1	Session 2	Session 3	Session 4
Themes	**Introducing Mindfulness & Self-Compassion**	**Blending Mindfulness and Self-compassion into everyday life**	**Compassion in Caring**	**Working with Difficult Emotions Exploring Gratitude**
Content	3 Circle Model of Major Emotion Regulation Systems (Gilbert, 2010b) Components of self-compassion What do I need now?	Emphasising kindness to self Practising in the moment	Caregiver fatigue Differentiating empathy, pity & compassion Using practices while caring	Exploring loving kindness phrases Gratitude & appreciation Resources going forward
Meditations & Practices	Soothing Touch Body Scan with Kindness Mindfulness in Daily Life	Affectionate Breathing Self-Compassion Break The Pause	Giving & Receiving Compassion Caregivers' Meditation	Loving Kindness for Difficult Times Gratitude & Savouring
Hand-outs	CD 1 (*Body Scan; Affectionate Breathing long & short; Self-Compassion Break; short Breath meditation; short Sound Meditation*) Defining MSC Components of self-compassion Gilbert's 3 system Model	5 Myths of Self-Compassion article Notes on SC Break & The Pause	CD 2 *(Giving and Receiving Compassion; Caregivers Meditation; Loving Kindness for Difficult Emotions; Gratitude Meditation)* Notes on empathy, pity & compassion	Explanation of Loving Kindness for Difficult Times – finding the right phrases Resources List

4.6 Quantitative Outcome Measures – Phase One

In order to determine which outcome measures to use for this study, reference was made to the MSC Pre-Post Assessment Packet (Center for Mindful Self-Compassion, 2015) made available to trained teachers of MSC. This contained details of a standard battery of eight measures to assess the impact of MSC on participants. It was essential not to over-burden Carers in terms of time commitment through the use of all eight measures and yet it was important to capture changes in self-compassion and psychological functioning (if indeed there were any). Consequently, to minimise the burden on Carers but to allow for as much detail as possible to emerge from the quantitative data two measures were selected, namely, the full versions of both the Depression, Anxiety and Stress Scales (DASS) and the Self-Compassion Scale (SCS).

Participants completed paper versions of the self-report measures prior to starting session one of iCare and then at post-intervention, generally prior to the start of the interview which was conducted approximately two weeks after the final session of iCare. Outcomes were the scores for the individual scales of DASS and both total and individual sub-scale scores for the SCS.

Depression, Anxiety, Stress Scales

DASS (Lovibond & Lovibond, 1995) is a 42 item self-report instrument designed to measure symptoms of depression (e.g. *"I couldn't seem to experience any positive feeling at all*"), anxiety (e.g. *"I was aware of dryness of my mouth")* and tension/stress (e.g. *"I found myself getting upset by quite trivial things*") during the past week. Participants rated items on a 4-point Likert scale ranging from 0 (*did not apply to me at all*) to 3 *(applied to me very much or most of the time*). It is suggested that this scale is valuable in measuring current symptoms of psychological distress in both clinical and non-clinical populations (Antony, Bieling, Cox, Enns, & Swinson, 1998) and has a high internal consistency (Nieuwenhuijsen, de Boer, Verbeek, Blonk, & van Dijk, 2003).

Self-Compassion Scale

SCS (Neff, 2003a) is a 26-item self-report inventory that consists of six sub-scales developed to measure both the negative and positive facets of the three main

components of self-compassion, namely: self-kindness, self-judgement, common humanity, isolation, mindfulness and overidentification. Items measure how individuals "respond to feelings of inadequacy or suffering" (Neff & Germer, 2017, p. 373) across these six facets e.g. Self-Kindness: *"I'm kind to myself when I'm experiencing suffering"*; Self-Judgement: "*I'm intolerant and impatient towards those aspects of my personality I don't like*"; Common Humanity: "*When things are going badly for me, I see the difficulties as part of life that everyone goes through*"; Isolation: "*When I'm feeling down, I tend to feel like most other people are probably happier than I am"*; Mindfulness: *"When something upsets me I try to keep my emotions in balance"*; and, Over-Identification: "*When I'm feeling down I tend to obsess and fixate on everything that's wrong"*. Participants rated items on a 5-point Likert scale ranging from 1 ("Almost Never") to 5 ("Almost Always). Subscale scores are reached by calculating the mean of subscale item responses (negative subscale responses are reverse scored) and a total self-compassion score is identified by calculating a grand mean of the six sub-scale means.

Both total self-compassion score as measured by the SCS and scores for each of the six constituent subscale scores were identified, as supported by Neff et al. (2019). Whilst the study is interested in identifying whether self-compassion can be learned, given that the research also aims to explore how self-compassion may impact Carer well-being it was felt valuable to examine these six sub-scale scores as these may add a nuanced interpretation to participant change (Neff et al., 2019). Neff (2003a) identified that both the total SCS score and the six subscales evidenced good internal reliability and consistency. Use of the SCS is not without its critics. Some argue that it does not measure what it is claimed to measure (e.g. Muris & Otgaar, 2020), which is strongly contested by Neff (2020a), but it remains the most used measure for assessing self-compassion. Muris and Otgaar (2020) report that in empirical studies of self-compassion over 95% used either the SCS or the short form version of the SCS.

The outcome measures adopted were all self-report measures and as such participant responses will have been influenced by a variety of factors impacting participants at the

time of completion. These include, but are not limited to, the health and well-being of their Caree.

4.7 Qualitative Data Analysis

4.7.1 Reflexive Thematic Analysis

TA is "a method for identifying, analysing and reporting patterns (themes) within data. It minimally organizes and describes your data set in (rich) detail" (Braun & Clarke, 2006, p. 79). TA looks across the data set (in Phase One the transcribed interviews) to identify recurring patterns of meaning. There are several versions of TA ranging from what may be called 'coding reliability' versions (Boyatzis, 1998) situated within a more positivistic approach emphasising reliability and accuracy in coding; 'codebook' approaches such as template and framework analysis or a new method, iterative thematic inquiry (Morgan & Nica, 2020) which whilst underpinned by qualitative philosophy adopt more structured coding approaches; and reflexive TA which is firmly situated within the qualitative paradigm, where teams of coders are not seen as a mark of quality and coding is more organic and open in nature involving a deep engagement with the data (Braun & Clarke, 2019b; Clarke & Braun, 2018). It is the latter approach to TA which most resonated with my philosophical and axiological stance, given that within reflexive TA researcher subjectivity is valued as a resource in producing knowledge and the inevitability of that knowledge being shaped by the researcher is accepted rather than seen as a dangerous challenge to validity (Braun & Clarke, 2020; Terry, Hayfield, Clarke, & Braun, 2017).

Reflexive TA can be used with most kinds of research questions, including questions about experience, lived experience, about people's views, about factors that influence or underpin phenomena, using reflexive TA to interrogate dominant patterns of meaning. Reflexive TA is not restricted to interview data but can be used to analyse a variety of data such as online forums, email communication, visual data, qualitative surveys and questionnaires (Braun, Clarke, & Gray, 2017; Clarke, 2017). Hence reflexive TA was considered well-suited to conduct the analysis of the qualitative data and provide the answers to the research question.

A critical realist philosophical approach to this research has been adopted hence it was important to utilise a method that was also compatible with that philosophical stance. Reflexive TA is not tied to any one theoretical position and thus can be applied within a number of epistemological approaches (Joffe, 2012). However, it is important to underpin reflexive TA with theory as it is not atheoretical (Clarke & Braun, 2018) and it comes without a broader theoretical framework, such as IPA where theory (phenomenology) comes prepackaged. As CR is "happy to accept the validity of a wide range of research methods without recognizing the primacy of any" (Mingers, 2006, p. 215) undertaking a reflexive TA of the qualitative interview data is theoretically and philosophically appropriate.

TA is not without its detractors. Concerns about the method's flexibility centre on a potential lack of consistency and coherence in developing themes (Nowell et al., 2017). Thorne (2020) criticises the potential for a superficial data analysis involving merely theme identification and that published research can fail to demonstrate the robustness that TA was intended to provide. Even Braun and Clarke agree with this position, commenting that there are too many examples of inadequate TA in circulation including cases of epistemological confusion (Braun, Clarke, & Weate, 2017). These criticisms are countered here by offering a rich, fine-grained coding, theme development and exploration, engaging fully with the interpretive potential of TA and being explicit about how TA is situated within CR. As such I consider that I meet Braun, Clarke and Weate's call to "flexibly and reflexively … produce analyses that "go beyond the obvious" and capture the messy, contradictory, and complex nature of psychological and social meanings" (Braun, Clarke, & Weate, 2017, p. 203).

There are various ways of conducting reflexive TA given its uniquely flexibility. For example, reflexive TA can be *inductive* generating an analysis from the data or *deductive* where the analysis is driven by an existing theory; *essentialist*/*experiential* capturing participants' meanings and realities or can be *critical* adopting a questioning orientation to mainstream understandings. Reflexive TA can also be *realist* or *constructionist*, or, as it is used in this study, as a *contextualist* method sitting between the two poles of realism and constructionism, acknowledging "the ways individuals make meaning of

their experience, and, in turn, the ways the broader social context impinges on those meanings, while retaining focus on the material and other limits of 'reality" (Braun & Clarke, 2006, p. 81). This flexibility permits the exploration of a topic from various theoretical positions which fit with the researcher's ontological and epistemological positions.

The qualitative analysis adopted in Phase One was predominantly inductive in a 'bottom-up' way, not driven by any theory other than Neff's notion of self-compassion (Neff, 2003b). The analysis will have undoubtedly been influenced by my insider status (Dwyer & Buckle, 2009) with pre-existing practical knowledge of counselling carers of those with life-limiting illnesses, of previously being a carer of people with life-limiting and palliative diagnoses and of teaching self-compassion and mindfulness interventions. Hence the process of data collection and analysis will have been conducted through this lens. In order not to influence the reflexive TA the analysis of the quantitative measures was undertaken after the reflexive TA had been completed.

4.7.2 Analytic Process

The process of conducting the reflexive TA was in line with the six phase model outlined by Braun and Clarke (2006). The data set subject of the reflexive TA consisted of the transcripts of the semi-structured interviews and the audio recordings of the interviews. The analysis, as explained above, was inductive and data driven. The initial focus of the analysis was on the semantic content examining the surface meanings of the participants' narrative but then moved beyond this to consider latent content which is the "*underlying* ideas, assumptions, and conceptualizations - and ideologies - that are theorized as shaping or informing the semantic content of the data" (Braun & Clarke, 2006, p. 84). This forms part of identifying causal mechanisms, an inherent aspect of adopting the critical realist framework utilised in this study. Heeding Finlay's (2011) suggestion that you should be as transparent as possible in describing the research process I detail below how I conducted the analysis of the Phase One data.

Phase 1: familiarizing yourself with the data The analysis started with the transcription of the data and several readings of each individual interview transcript. A hard copy of

each transcript was printed, and initial notes and impressions were written on the righthand side of the transcript with words or sentences forming nascent ideas underlined.

Phase 2: generating initial codes Each transcript was systematically reviewed and preliminary codes were handwritten on the right-hand side of the printed transcript. Originally it was intended to use note cards to capture codes and data extracts but it quickly become clear that this would prove to be unmanageable. Consequently, each participant transcript was then copied and pasted into a new Word document which allowed for data extracts to be highlighted and using the Word Review function to create initial codes (as Comments), again on the right-hand side (see Appendix 8 for examples of coded data).

Phase 3: searching for themes The initial codes together with participant number and line reference corresponding to the relevant data extract were then moved into an Excel spreadsheet. This was then used to sort codes into potential themes, moving codes as appropriate into different themes and then sub-themes.

Phase 4: reviewing themes The data extracts for each theme were then reviewed to assess for coherence and consistency. This involved moving some codes into different themes, reworking themes or discarding themes. At this stage a mind-mapping tool (Coggle.it) was used to create a thematic map (see Appendix 9 for examples of thematic maps). This was reviewed and refined several times. Initially ten themes were identified with 60 sub-themes, far too many themes and sub-themes for a rigorous thematic analysis and it necessitated a complete review and refinement of the analysis as described in Phase 5 below.

Phase 5: defining and naming themes In light of the publication of Clarke and Braun (2018) it was clear that the analysis consisted more of under-developed themes as domain summaries rather than 'storybook' themes, which are more interpretive and creative with a central unifying concept and which are considered to be the hallmarks of a good reflexive TA (Clarke, 2017; Clarke & Braun, 2018). The thematic map was then

further reviewed and refined which involved a further re-evaluation of the analysis and the definition and description of the themes. Themes were then refined and renamed and a final Coggle mind map created which reflected four themes and 10 sub-themes.

Phase 6: producing the report This phase encompasses the final analysis and a convincing and evidenced written account of the story being told by the data. The results of Phase 6 can be found in Chapter Five.

A thorny debate in qualitative research is data saturation (e.g. Low, 2019; O'Reilly & Parker, 2012; Saunders et al., 2018); it is commonly assumed to mean sufficient data has been collected and/or analysed such that further data collection or analysis is not required. The difficulty arises with confusion about how to conceptualise data saturation or even if it is an applicable concept to apply to all forms of qualitative research (O'Reilly & Kiyimba, 2015). In relation to reflexive TA Braun and Clarke (2019c) question its usefulness. Given their view of TA which is "that meaning is not inherent or self-evident in data" (p. 10) but requires the interpretation of the researcher to create meaning it is always possible that new meanings are conceivable (Low, 2019; Sim, Saunders, Waterfield, & Kingstone, 2018) and therefore saturation is unattainable.

Throughout the latter stages of the analysis the process of identification of themes was discussed with my supervisor in supervisory meetings. The final analysis and findings were checked against Braun and Clarke's 15-point checklist of criteria for good thematic analysis (2006).

***Reflexive Comment**:* My *insider status (see above 4.7.1) may have facilitated rapport and understanding between myself and participants which was useful for the interview with participants. Yet I also held an outsider perspective to the research (Dwyer & Buckle, 2009) regarding differences in the relationship with people I cared for, my occupation and the role adopted in the research process as both facilitator and researcher. Echoing the contention made by Adams, McCreanor, and Braun (2013), I consider that "This resulted in a mix of insider knowledge and outside professional distance being applied" (p. 890).*

4.8 Statistical Analysis

Quantitative data from the DASS and SCS instruments were scored and analysed using SPSS25. Pre-intervention scores were obtained prior to commencement of the first iCare session and post scores were collected at the time of the research interview, approximately 14 days after completion of iCare. Participants completed paper versions of the SCS and DASS measures. One item score was missed by two participants one in the pre SCS and the other in the post SCS. These related to the Isolation and Common Humanity sub-scales respectively. Following Badr (2020), these missing scores were imputed by calculating the mean of that participant's remaining Isolation or Common Humanity scores and imputing that value. For the DASS measure one item was omitted by a participant in the Stress sub-scale. In line with Lovibond (2020) this missing score was addressed by calculating the mean of that participant's remaining Stress scores and imputing that value.

The results were tested for normality and all measures were normally distributed. For the variables, a series of paired sample t-tests were used to determine if there were significant pre/post changes in the self-compassion (SCS) and depression, anxiety and stress (DASS) variables. Statistically significant differences were defined with a 95% confidence interval when excluding the zero value and with a level of significance of $p \leq 0.05$. It can be argued that whilst the quantitative data help to enlarge on the qualitative data, because of the small sample size it is likely that there is insufficient statistical power for the t-test to be statistically significant (Twigg & Redford, 2015, p. 154). Given the small sample sizes (n=9) it was decided not to calculate an effect size using e.g. Cohen's d, as it can over-inflate effect sizes in small samples of n=<20 (Lakens, 2013). More in-depth statistical analysis involving correlations was also not conducted, again due to the limited number of participants (see e.g. Aggarwal & Ranganathan, 2016). Percentage changes, pre/ post, in scores are reported.

4.9 Summary

This Chapter has presented the method for collecting and analysing data for Phase One of the study. This has included a detailed exploration of reflexive TA, the chosen analytic method of the qualitative data, descriptions of the quantitative measures used together

with a description of the content of iCare, the intervention participants experienced. Within the next Chapter the findings from the analysis of data from Phase One are presented.

Chapter Five: Findings Phase One

5.1 Introduction

In Phase One of the study, each participant was asked about their experience of the iCare programme using a semi-structured interview. The research interview explored the participants' experience of the various mindfulness and self-compassion practices they were introduced to, the format of the iCare programme, what self-compassion meant to them and what changes, if any, they had noticed in themselves post iCare. Additionally, participants were asked to complete two self-report measures before starting iCare and after completing iCare. Whilst the quantitative data is not the primary focus of the study, as it is the participants' experience of iCare that is of most interest, it was thought that the data from these measures would add further insight and potentially help in identifying causal mechanisms. Before the findings from Phase One are presented a brief summary of Phase One participant biographical details is outlined.

5.2 Biographical background

All participants were White females aged between 38-78 with Carees aged between 39-81, some living with their Caree others caring at a distance. The mean age of participants was 58 and the mean length of time the Caree had received their diagnosis (and assumed period of caring) was approximately five years and eight months. Brief biographical details of Phase One Participants are detailed in Table 3 below supplemented with more personal information in the following paragraphs.

Table 3

Biographical Details of Phase One Participants

Name of Participant	Age of participant*	Relationship of Caree to participant	Age of Caree*	Diagnosis of Caree	Approximate time since diagnosis*
Beth	60	Husband	60	Parkinson's Disease & Multiple System Atrophy	10 years & 8 years respectively
Dawn	50	Father	72	Prostate cancer and Chronic Obstructive Pulmonary Disease	11 years & 6 years respectively
Emily	68	Partner	69	Motor Neurone Disease	2 years
Isabel	52	Friend	49	Motor Neurone Disease	1 year
Karen	78	Husband	79	Cerebral Vascular Dementia	12 years
Linda	57	Mother	81	Cancer	3 years
Olivia	63	Husband	69	Spinocerebellar Ataxia	2 years
Sophie	56	Mother	80	Vascular Dementia	2 years
Tamsin	38	Wife	39	Cancer	9 years

*At date of completion of initial pre iCare biographical questionnaire

Beth had recently taken three months off work as a cleaner to care for her husband and to review her situation. They lived together in their own home, but adaptations had been made and would be made to the home to enable Beth's husband to be cared for at home as his condition deteriorated.

Dawn was a Carer for her father. He lived independently some distance from Dawn, with the help of carers. Dawn described both of her father's conditions as being in the terminal phase. Dawn lived on her own and had a demanding career that she left during her participation in the study. By the time of her research interview she had recently started working in a supermarket, latterly as an internet 'shopper'.

Emily was sole Carer for her husband. An engineer by background she had operated for many years her own consultancy business which she had gradually run down to enable her to care for her husband. Emily lived with her husband although explorations were beginning into the availability of day centres or other avenues that might offer some respite from caring.

Isabel was married and a mother of a teenager as well as Carer for her friend. Additionally, she was also a Carer for her elderly mother and another friend with ovarian cancer. Isabel worked in a hospice as a volunteer therapist.

Karen lived with her husband. In addition to his diagnosis of dementia other comorbidities were diabetes and lumbar canal stenosis. They lived together in their own home and at the time of the study Karen's husband was still able to leave the house for short periods on his own.

Linda was a Carer for her mother. Linda lived on her own and was in the process of going through a contentious divorce. She worked in a local garden and homeware store. Her mother lived locally with Linda's father.

Olivia was sole Carer for her husband. She had previously volunteered in a hospice but had given that up to care for her husband.

Sophie was a former legal professional who was now retraining in a different career and who was main carer for her mother. Sophie had made the decision, with her siblings, to move her mother from a distant part of England to a care home near to Sophie.

Tamsin was sole Carer for her wife. Tamsin worked as a healthcare practitioner. She anticipated relocating after her wife's death, something that she and her wife had both hoped to do but which was thwarted by her wife's diagnosis.

Table 4 sets out the time taken by participants to complete the iCare intervention and the associated research tasks. The mean time taken to complete iCare and the post iCare interview and self-report measures was 51 days (just over seven weeks).

Table 4

Days Taken by Participants to Complete all Four Modules of iCare, Post-iCare Self-report Measures & Complete Research Interview

Participant	Days taken*
Beth	40
Dawn	76
Emily	70
Isabel	81
Karen	36
Linda	43
Olivia	38
Sophie	43
Tamsin	31

*Research interview and post outcome measures completed between 15-22 days after completion of module 4 other than in the case of Tamsin with self-report measures completed two days after finishing Module 4 and interview conducted 91 days after the start of the intervention.

In the pre-iCare biographical details questionnaire two participants described themselves as having some experience of meditation as shown in Table 5.

Table 5

Phase One Participants' Prior Meditation Experience

Name	Regular practice of meditation?	Description
Isabel	Yes	Yoga & mindfulness 20+ years
Sophie	Not currently	However practised TM [transcendental meditation] on and off over a few years

5.3 Qualitative Analysis

Four main themes and 10 sub-themes, as shown in Table 6 below were developed from the analysis of the interview data and these are explored more fully in the following pages.

Table 6

Phase One Main Themes and Sub-themes

'***This is what people that are self-compassionate do***'	**A Compassionate Presence**	**On Being a Student**	**In the Trenches**
'*permission to be kind to myself*'		Maintaining Curiosity	Soldiering On
Being Your Own Best Friend		Engaging with the Curriculum	Wounds of War
Heart Opening		Absorbing Theory by Osmosis	Line of Duty
		Evaluating iCare - Gains and Pains	

5.3.1 Theme: '*This is what people that are self-compassionate do*'

The overarching theme '*This is what people that are self-compassionate do' (*Tamsin, 220) captures the growing understanding that participants experienced through their journey with iCare. It is almost like an 'aha' moment of insight into what self-compassion feels and looks like. Participants commented on the changes in themselves

across a number of dimensions but at the core is an impression of a developing awareness of what it is to be self-compassionate. This in turn is represented by participants giving themselves permission to take care of and prioritise themselves, becoming their own kindly best friend and a sense of opening their hearts to themselves. These three sub-themes of '*This is what people that are self-compassionate do'* are interconnected with an ebb and flow between sub-themes rather than there being a linear connection from say allowing themselves to practise self-care leading directly to heart opening.

Sub-theme: *'permission to be kind to myself'*

Carers struggle to allow themselves time off from their caring responsibilities and do not easily practise self-kindness and self-care whereas self-compassionate people give themselves permission to take care of themselves and when appropriate to prioritise their own needs. Often Carers look outwardly for this permission to be bestowed by another. As participants moved through iCare there were some shifts in this position which could be seen in the interview data. iCare encourages self-care and self-kindness which seems in turn to foster a more internal gaze. This was expressed by some participants as gaining a permission to practise self-kindness and self-care. For others 'permission' whilst not explicitly stated could be identified from participants' action as they allowed themselves to recognise their own needs and then to practise greater self-care.

Participants prior to starting iCare externalised the bestowing of permission to prioitorise their own needs - this may be to a partner or unnamed others. Participants seemed initially unable or unwilling to identify that they too had their own needs which needed attending to. This is most likely to reflect the wider societal assumption that Carers are unselfish, giving and fully self-sacrificing. Participation in iCare appears to have changed this. Given that society at large does not seem to encourage self-care and recognition of your own needs as a Carer it seems to have been a revelation to participants that they themselves could take ownership of their own needs.

Olivia commented that iCare gives Carers permission to focus on themselves, that it was allowed:

> *I know it's okay…the concept is to be compassionate towards yourself and to be kind towards yourself, erm I just didn't think of it before, so its brought it into my awareness* (240-244).

Emily echoed this sense of permission giving:

> *it's as if it's given me permission to be kind to myself, which has not been something that's ever really been explicit in there, in my head* (122)

and Tamsin felt that she was "*giving myself permission to do things* "(144) without needing her wife's permission "*And I've got the permission …I don't need [*Wife's*] permission to do things*" (152). Through giving themselves permission to acknowledge their individual needs participants were able to make decisions to meet these needs such as Beth who knew that she needed to join a gym as obviously "*I need time out*" (13) a need Linda echoed "*sort of just taking that time out a bit for yourself*" (50) or staying out longer and not rushing back to the Caree.

Sophie commented on the unselfish aspect of permission giving - it is not a selfish act to meet your needs "*you're not selfish, you're allowed to have [*compassionate breath for self*]*" (86). Isabel concurs and points out that caring for yourself is a win-win for both Carer and Caree as "*it's not a selfish thing to do, it is selfless really because the end product is that they [*Carers*] can give better care and function better in their caring role*" (82). These comments about whether giving yourself permission to practise self-care is selfish or not may point to unspoken feelings of guilt about Carers taking care of themselves and a need to justify self-compassion. Tamsin is the only participant to articulate that giving herself permission to meet her needs, to be kind to herself, is done without feeling guilty which seemed to be a significant factor to her "*and not feeling guilty for it, that's the biggest thing*" (208).

Olivia powerfully sums up the essence of this sub-theme when she says that iCare is about allowing herself "*to turn the focus to me rather than the focus to [husband]; it's all*

right to focus on me, you know, I have needs" (21). This is the essence of iCare: encouraging Carers to see that they matter too in the midst of their caring responsibilities, rather than denying that they have needs and feelings.

In recognising their needs and in allowing themselves to meet some of them, participants practised self-care in a variety of ways. For Karen, her self-care involved "*pottering in the garden"* (102). Beth was taking three months out of work to think through her options and during this time planned to join a gym because she felt this would give her time out, something she felt she needed. In fact, time out could be as simple as just popping out to the shops, getting away, albeit briefly, from caring responsibilities. Beth recognised that she was "*thinking more, 'look after yourself more' you know*" and that gym and pool were active steps in taking care of herself. Physical exercise was also valued by Isabel as important for her self-care:

> *And exercise for me, I do quite a lot of sport so that that always helps me, but everybody has got their own thing haven't they? That works for me* (58)

Sophie gave herself permission in one of the guided practices to prioritise her own needs rather than think she needed to prioritise her Caree. Other types of self-care included inhaling lavender or rosemary plants or using aromatherapy oils to self-soothe:

> *when I do get fed-up and when I do get miserable I just think 'oh it's normal, just let it go, just breathe through it' or I'll do my rosemary and my lavender or if I am at home one of my oils and I just think 'right that's ok now'* (Linda, 18).

Self-care was a new experience for some and, as such, some Participants were tentative in practising it. Emily talked about "*starting to think more of how to build a bit of me time into, into life*" (146) and that she was "*learning to put myself first, or at least on an equal footing*" (154). Yet once she had become more comfortable with what she described as the "*tools and mechanisms"* offered through iCare she became more *"able*

to think of yourself rather than just the person who's, who's the object of the caring" (118). This resulted in some beneficial practical changes. Her husband did not sleep well and frequently disturbed Emily's sleep, as a result, she was tired and longed for a good night's sleep. For the first time she allowed herself to sleep in the spare room once she had established that her husband could make himself heard if he needed help and the result was "*I got the most amazingly good night sleep which was lovely*" (158). Having scored this success, she was then able to prioritise her sleep in further nights.

Tamsin, having been encouraged to actively practise self-care through iCare embraced the concept and had no hesitation in describing the various ways she was taking care of herself or allowing herself to take time away from her wife and "*not feeling bad for it, or not thinking I'm not worthy"* (140). Tamsin's self-care activities included nurturing her body through healthy food or following a beauty regime, attending a local music concert on her own or just having a cup of tea and sitting and giving herself "*me time*" (212). Interestingly, several times Tamsin talked about 'giving herself' permission to do things or giving herself time to herself. She was keen to point out that *she* was giving herself the permission, she wasn't seeking it from her wife, and she didn't feel bad or guilty for doing these things. Tamsin is clear that these changes have been as the result of iCare "*it's nice for me to look back and say like two months ago I never would have put myself first"* (432).

The active recognition of their own needs through listening to themselves propelled participants to practise self-care including making changes in how they physically cared for themselves. For Beth it was making more effort to exercise through joining a gym and swimming *"joining the gym and things like that*" (133) and generally trying to be more positive in her approach to life. She seemed surprised that she had arranged a manicure for herself, something that did not normally appear in her usual self-care activities. Tamsin actively chose to nurture her body through eating more healthily and practising self-care:

> *And there's only so much cake you can have at one time, and now it's like, when I'm stressed instead of reaching for a cake or a bar of chocolate I just think*

> *'what else can I do to make myself feel better?', so I've bought myself flowers a few times, bought more olives.* (Tamsin 196)

She was also planning on starting at a gym but in the meantime, she was allowing herself time to take walks with her wife. Tamsin attributed this change in how she was looking after herself to a change in how she felt about herself "*I'm kind of …loving myself a bit more I think"* (200) which is an element of heart opening.

Self-care can involve quite significant changes which Dawn embodies. She actively chose to give up a high-powered job "*I've actually got myself a part-time job at Tesco's*" (74) which she enjoyed; making connections with others, being able to leave on time and generally discovering a more stress-free way of living. Yet for two participants self-care must be justified as a way of improving their caring. This hints at the struggle to fully embrace the notion of being kind to themselves, rather self-care is conditional upon becoming a better Carer, perhaps to ward off potential criticisms of being perceived as selfish. Linda felt that practising self-care could enhance her caring "*you are not taking anything away from the person that you are caring for but you're actually giving yourself a better chance to care*" (44). Isabel, an experienced caregiver both professionally and personally, echoed this when she said she would recommend iCare to other Carers because

> *in order for them to sustain their care for their patient they need to sustain their own self-compassion … it's invaluable or else you can't keep going, you will crash* (82)

iCare was created with regular prompts and nudges towards self-care which may be why every participant in one way or another referred to acts of self-care. Self-care was clearly embedded in how participants understood and conceptualised iCare. Participants were asked how they would describe iCare to other Carers. Descriptions of iCare were generally simplistic and centred around a sense of 'taking care' of yourself. For example, Karen defined the programme as basically "*it is just looking after yourself …taking care of yourself … without making yourself a Princess*" (96-102) clarifying that self-care was

not about being self-indulgent and narcissistic. Linda pointed out that iCare was similarly "*about caring for yourself*" (44). Echoing this sense of self-care Tamsin explained that for her iCare was about putting herself first without guilt. Later in response to a question about describing iCare to other Carers she encouraged them saying:

> *…do you ever put yourself first, as in your own needs or wants, err, do you find that you're spending all your time caring and you've got no time to do anything else at all other than sleep, exist, and have a go at it to see if it changes the way that you look at things, the way that you look at yourself in terms of …you are a carer, but it's not who you are wholly, you're still a person and you've still got needs and you've still got you that needs nurturing. (228)*

In this description iCare to Tamsin is about allowing the whole person of the Carer to be met, addressed and nurtured not just the part that cares.

Emily focused on both prioritising self-care and the practicality of iCare in defining the programme as it had given her:

> *tools and mechanisms to be able to think of yourself rather than just the person who's, who's the object of the caring, and its tools to learn to be kinder to yourself* (118)

The support and gentle prompts to practise self-care woven through iCare have been taken up by participants and flow through their discourses around iCare and what it means to them. It seems as if participants were waiting for permission to be kind to themselves - what iCare offered was an encouragement ultimately to find that permission for themselves.

Sub-theme: Being Your Own Best Friend

Part of what self-compassionate people do can be described as becoming your own best friend. Offering yourself guidance, loving support and care particularly during stressful

and difficult times. Indeed, this is specifically referred to by Olivia who says "*So the self-love, self-love and um, it's all about like being your, being your best friend, isn't it? That's how it feels*" (156). Being your own best friend involves turning towards yourself, trusting yourself and having an internal locus of evaluation, such as described by Tamsin "*I was thinking in terms of for myself, 'could I handle this situation on my own, am I happy to be here…*" (164), rather than deferring to an external third party for approval, in Tamsin's case her wife. In becoming your own best friend though there is also a wise voice, rather than a self-indulgent one - knowing when to exercise, when to eat more healthily and when it is important to prioritise your own needs (e.g. for sleep). This can be seen in Tamsin's changes in her eating patterns described in sub-theme '***permission to be kind to myself***'.

Another facet of being your own best friend was the change that occurred in the participants' internal monologue or self-talk. Frequently people find that self-talk provides a running, generally negative and critical commentary on how they conduct themselves in day to day life. Your best friend is very unlikely to speak negatively and critically to you, they generally are supportive and caring and whilst they may offer challenges occasionally this is done within a loving framework. Olivia was clear in identifying that she now talked to herself differently post-iCare, in that her self-talk was kinder and more supportive:

> *Just to sort of say, you know, 'don't beat yourself up on, about this' or you know, 'it'll pass', that, you know, that sort of thing* (52)

Linda describes how she used to speak critically to herself and whilst she may start to talk this way, she is now able to be more sympathetic and rational in her inner dialogue:

> *Yeah I think before if it was really getting me down I would say 'oh you've been so stupid, you've been this, you've been that, you've been the other, and sometimes I'll start with 'oh what stupid things you did', and then I'll think 'well if I hadn't have done them I wouldn't be here', so it's done. So I think that comes a lot quicker and then I think just 'it's done, its fine' (148)*

Participants may continue to fall into old habits and ways of speaking to themselves, but now seem to spot that this is happening and then change the tone of their inner talk. For example, Sophie starts using derogatory language to herself but then remembers that she's trying to be more self-compassionate,

> *But what initially happens is, you know, I might be beating myself up or something and then I remember, oh, no, and start soothing myself* (2).

Dawn reports that she does something similar and cites her struggles with one of the meditations in iCare "*part of me thinks 'oh don't be daft', but then I know that's part of sort of being kind to myself if you like, that sort of it's a valid thought, it's not daft*" (46). For Beth it is about adopting a more supportive, almost coaching tone to her inner dialogue:

> *I've been thinking about it and trying to make myself happy … I've said, 'this is going to be better with [partner] with his stuff and I'm going to join the gym' and trying to work things out that make me feel better, you know things like that* (45)

<u>Sub-theme: Heart Opening</u>

Heart opening endeavours to express the sense of participants tentatively turning towards themselves as individuals with tenderness, and as such recognising their own needs, opening their hearts to themselves and hearing their own inner voices. Heart opening for participants appeared to lead to nurturing acts of self-care. This can be contrasted with participants' prior near-constant attunement to their Caree's needs which drowned out the voice of their own needs. An awareness of the beauty of life or gratitude for what currently is, also reflected the expanding emotional heart as did changes in how they nurtured and took care of themselves.

Perhaps heart opening can be best summed up by Tamsin when she describes how towards the latter sessions of iCare "*I started seeing me more*" (212). As a result of 'seeing'

herself she was then able to acknowledge what she needed to nurture herself and then take steps to care for herself.

Emotional changes were at the core of 'heart opening'. In the third session of iCare, Tamsin found herself in tears, which was a new experience for her having kept her feelings contained for many years. In the research interview she reflected on the significance of 'heart opening' to herself citing this as one of the memorable moments of iCare. This sense of softening or letting down barriers was echoed by Beth, *"I've cracked a few of the bricks you know and broke them up a bit"* (129), who had previously referred to building a wall around herself for protection. Sophie's 'heart opening' was a sudden profound awareness of the equality between herself and her mother and others in the care home, that despite her mother's vulnerability and physical and mental decline "*you're equal human beings, you're equal and it just suddenly felt it, like I hadn't felt it before*" (198); this was a tangible feeling located in her chest. This sense of common humanity (see sub-theme ***Absorbing Theory by Osmosis***) appeared to touch her deeply.

For Linda, heart-opening came through expressing feelings of gratitude for moments of connection and appreciation with nature. She described her early morning journey back from the airport:

> *Coming back it was lovely because the motorway was still quite empty…and there was like a lovely sort of mist all over …and the trees and …it was just so nice, so then you notice and then that's when you're thankful 'cos you're seeing things that make you feel…. (Linda,100)*

Dawn's heart opening to herself manifested in a more smiley demeanour, something quite different to her normal manner which was commented on by work colleagues

> *I had a meeting last week with one of the managers and she said 'you're very smiley', and nobody has ever, ever said that before; people have always said 'god what's the matter with you, smile will you?* (313).

She seemed surprised at this change and in her interview, she gave off an air of amusement at this 'personality shift' and how easy the transformation had been.

This theme has attempted to capture the participants' descriptions of a warmer, kinder way of treating themselves be that through inner talk or behavioural changes, stemming, so it would seem, from finding a permission to recognise that they too have needs which can be met.

5.3.2 Theme: A Compassionate Presence

The participants easily talked about positive changes that had occurred following iCare and yet woven throughout their interviews were subtler references to the presence of me as facilitator and an undefined element to iCare which here is termed as 'A Compassionate Presence'.

Reflexive Comment: *It was uncomfortable to acknowledge the impact that my presence appeared to have on participants. However it was only in the latter stages of the study that I realised after participating in some online MSC training that as teachers of MSC we are encouraged to offer to course participants a 'loving connected presence' and it is this that the participants seem to have highlighted. As McGehee et al. (2017) suggest "* The best way to teach self-compassion is to *be* compassionate. Students learn self-compassion by internalizing how their teachers embody compassion—loving, connected presence" (p. 290).

It appears that as a facilitator I offered a warm, reassuring connection with participants commenting on the personal, face to face interaction iCare provided:

> *on a human level it was a person to person* (Karen, 150)

> *it is nice interacting with another person* (Olivia, 80)

> *the sessions where you are sort of, I'm sitting here and you're, you're taking the place of the tape if you like, but it's more personalised* (Emily, 210)

Sophie touched on this personal engagement:

> *I wouldn't want to let you down or anything. You know, I've made that appointment, that time. Um, and obviously it's much nicer talking to you than it would be to a computer, isn't it? (266)*

When she later makes some further comments post interview it is perhaps as a result of this engagement that she reflects on the motivating effect of knowing that she would be seeing me each week; there was a desire to maintain contact after the end of the programme to "*share progress and help keep us motivated*" (88,7). For Sophie, like others, there was something about the connection with me on a personal level. She commented about my "*lovely, warm, reassuring presence*" (88,38). When Emily is asked what stands out for her from the whole programme she says "*I think top of the list is, is yourself because you're, you're very calm and modulated and soothing, [laughs]. I think it's soothing*" (66). Karen also comments on the soothing and calming nature of my voice and my presence as a pacifying third party in the room as she played one of the practices attempting to calm the angry atmosphere between herself and her husband:

> *that break of us both sitting there from being hugely angry with one another and then having that break that wasn't just a break between [husband] and I, there was your voice there, there was different, you know, there was something else erm…and it was very soothing and very calming (32)*

For Beth, a Compassionate Presence enabled her to feel safe enough to disclose personal information and to know that that she was able to be heard "*maybe you're an easy* (sic) *listener*" (185) and Beth could get:

> *stuff off your chest and just a bit how you're feeling, and in yourself that helps you, because it's what you're thinking but not saying, so it's just coming to talk and you feel someone else is listening* (85).

Participants also referred to the gentle pacing of iCare, "*it's not felt like anything's been forced or rushed*" (Dawn, 293). Overall, the participants appear to value the warmth, sense of calm and gentleness that was offered through iCare.

Despite the valuing of the sense of connection and intimacy with me as facilitator this theme may be addressing more specifically the generally unspoken sense of isolation and even loneliness felt by some participants that iCare recognised and responded to. Through iCare there was a reason for participants to step away from their caring responsibilities, have a break, yet under the auspices of helping themselves to help their Caree. They also had someone who was there just for them. Emily touched on isolation and her connection with me, when commenting that one of the things that was noticeable for her about iCare was "*perhaps I didn't feel quite so alone"* (70) and she was visibly moved as she said this.

Given that the face to face version of iCare was intended to be a precursor to an online version, participants offered views about the format and delivery of an online version. Their comments point to what they valued in the face to face version which again touched on the importance placed on my presence and the challenge of replicating this online. Isabel stressed the need to be authentic online and refers to 'engagement' implying that she felt engaged with me during iCare:

> *just be very real with it because people will either engage or they won't but they will know if you are not fully engaged on whatever level*" (185)

How to engage with online users concerned several participants. Isabel felt that by recreating the face to face version of iCare online would result in engagement by users:

so they can sit wherever they are and you can talk them through the process. Then you're engaging with them, you might do that visually, or whatever, or it might just be an audio recording (98).

Emily commented on the impersonal nature of online courses but felt that there could be small ways to "*make it feel personal*" (282), for example, by acknowledging a user's experience through email. Sophie suggested that using my voice in the online course would be a positive step for building rapport with users. Karen added that seeing me rather than listening to a disconnected voice would draw her into an online programme:

if you introduced it, you explained it and you are there as a short video of you introducing it, explaining it and explaining the kind of benefits etc, then you would pull me into it in a way that you wouldn't if you, if it was a just go online and hear these meditations (156)

Some participants were concerned about the lack of interaction that an online version offered. Karen was clear that working online "*you don't get that bit of actual proper interaction*" (224), something which was valued by several participants. The participants' comments about an online version point to some concern about the potential for a lack of engagement with a facilitator in an on-line version, something which they had clearly valued in the face to face version. Replicating a compassionate presence online encompassing engagement, authenticity, connection and warmth was questioned.

5.3.3 Theme: On Being a Student

Through iCare participants were undertaking a short training in self-compassion. Even if they did not recognise themselves as such they were in fact students and their descriptions of the programme and how to approach it reflect this. This theme attempts to capture their experience of wrestling with learning something new and the impact of the syllabus. Participants appraised iCare and provided feedback on the programme and this is explored in the sub-theme **Evaluating iCare - Gains and Pains** where participants reflect on iCare and the impact it has had.

Sub-theme: Maintaining Curiosity

The participants came to iCare with a certain mindset and they had views about how other Carers should approach iCare based on their experience of the programme. Participants encouraged other would-be participants to adopt an attitude of curiosity. Most of the participants initially held a natural curiosity about iCare, wanting to learn something new or they wanted to find out more about an intervention targeted at Carers. Linda's said she was "*exploring anything and everything*" (58) to be the "*best that I can be"* (58); whether this was to be the best version of herself or herself as a Carer is not clear. Sophie's interest came from a past interest in meditation and an intellectual interest in other compassion focused work and she was looking for a specific training. Tamsin had been introduced to some ideas around self-compassion in counselling work many years earlier and she was clear "*from the onset it was more 'I want to do this'*" (232). In contrast, Beth saw the programme as a way of exploring some of her feelings *"I think it's just something I wanted to do, it was getting too bottled up in here"* (173) rather than acquiring knowledge.

Participants encouraged would be-participants to "*go with an open mind and to, and just be prepared to go along with it"* (Olivia, 29) but to allow for the individuality of experiences. For example, Karen pointed out that no two Carers will experience iCare in the same way "*because no two carers are experiencing the same"* (208), something Emily recognised *"what I might feel a bit …somebody else won't"* (318) and Isabel commented that *"It's not necessarily right for everybody"* (117). Linda captures that sense of maintaining an openness to iCare despite not initially feeling that positive about it:

> *because I mean the first one I came to I went away thinking 'hmm, not sure it's for me', but to be fair how can you know from one session whether it's for you or not anyway, so I think if you come and you just think to yourself 'well okay I need to be a bit more open about this and just give it a go'* (152)

'Being curious' also incorporates a sense of sticking with iCare to see what happens and it is that element of persistence that then gets results. There is clear encouragement

from some participants to persevere with the programme despite initial frustration. Dawn was originally uncertain about iCare but as she says,

> *Just because it doesn't work the first time doesn't mean it's not going to work for you; try it a few times and try it in a few different places, different environments* (233).

The second session is seen as the beginning of a turning point for some participants. Dawn's experience was that by the second session she was beginning to see both the intellectual and physical benefit of iCare and as *"'this works', so then you get a feeling of positivity"* (261) which in turn motivates you to give it another go. Sophie also encourages other Carers to:

> *hang on in there and if you go through, initially, if you go through a phase where you forget to do it or something, then don't, obviously again, beat yourself up. Just, you know, go back to it … I think that's happened initially the second week and then, it just became more natural. I'd say, yeah, stick with it.* (192)

Emily took a while to get into iCare, to get used to it and accept the principles before she began to see benefits. This was Linda's experience too:

> *At the start I just thought 'Hmm all this compassion for yourself is a bit, not something that I had been used to doing'. And I think once you keep listening and keep trying, it does sort of go in* (72)

iCare is unlikely to have immediate results; participants caution other Carers to stick with the programme and to continue practising even if initially nothing positive seems to be happening. Tamsin suggests advising Carers that it is not too onerous in terms of time involvement "*it's only so many weeks and in those so many weeks you may see a change in yourself for the positive*" (236). Participants concluded that keeping an open and curious attitude combined with perseverance was ultimately worthwhile.

Sub-theme: Engaging with the Curriculum

iCare was offered to participants with an encouragement to try the variety of practices on offer but to know that not every one would appeal. Whilst each session had a specific orientation and framework with set content to be delivered (see Table 2), essentially participants were invited to a buffet or a smorgasbord of practices from which to choose those that resonated most with themselves. A proviso was offered that it was useful to 'taste' practices at least a few times before making a final decision as to their value and usefulness, knowing that it can take time for certain approaches and practices to have an impact. Freedom to choose was encouraged, with an endorsement to participants to trust their own knowing, to take what they liked and discard what did not fit for them. This is reflected in the words of Dawn who says

> *find the bits and take the bits that work for you; it is it's not …all of it isn't for everybody, but take what works for you* (154)

This emphasis on flexibility and freedom within iCare contrasts with Carers' lives generally, which are constrained by medical appointments, giving medications to a set timetable and meeting Caree needs.

Through iCare, participants are encouraged to practise several formal guided meditations, ranging from approximately 5-20 minutes in duration, as well as incorporate informal practices into daily living. There are also small amounts of didactic teaching about the underpinning theory in the programme. This theme explores how participants grappled with the iCare curriculum in their day to day lives. As the findings from Phase One provided an empirical basis for the content of iCare-online it is useful to get an understanding of participants' experiences of the practices on offer.

Shorter practices, generally less than 10 minutes, were more accessible to participants, which is logical given the time pressures that Carers are under. Shorter practices also had the advantage of reducing the risk of being interrupted by their Caree:

> *the value of the short ones is, is knowing that I can say to [husband] 'I've got something to do, I don't want to be interrupted for a while', but knowing that he will feel the need, possibly, to do so, erm, so being able to do the shorter practices means that I can reasonably confidently know I won't be interrupted* (Emily, 106)

Linda agreed that they fitted into life more easily, and Tamsin gave the example of using the three Minute Breathing Space sitting in her car or even playing a practice on speaker phone when she was on her own at work. Tamsin was not alone in using the car as a space for meditation. Dawn tried a practice in her car when she had a gap between appointments and found that useful:

> *and then it just becomes easy to to leave it in the car or to have it in my handbag so that I know I can do that when I've got some when there's some lag or whatever, or I feel I need it and want it* (237)

From thereon in it became her favourite place to practise. Participants seemed comfortable being flexible where they practised (be that car, work, in bed, alone or with the Caree in Karen's case), and this flexibility extended to adapting the wording of practices to fit their needs.

Sophie commented that initially she was apprehensive that she would be expected to adopt a rigid approach to practising, possibly due to her earlier experience with another meditation model, but she then relaxed into it when she realised that this was not necessary and "*I have sort of tailored it to myself and just gone with what I like and use it spontaneously"* (188). As such, practice became less like homework with all the negative implications that can carry. The presentation of the iCare programme emphasises participant autonomy and encourages participants to trust themselves as to what they need to do regarding practice. Whilst there was gentle encouragement to practise regularly this was by no means an absolute command and this seems to be borne out by the participants' ease and willingness to be flexible with both wording of practices, timing and venue for practice.

The ethos of iCare (self-kindness, valuing and respecting your own needs and accepting what is) seems to have been absorbed by some participants, almost without noticing as a few talked about their spontaneous use of practices and the subtle effectiveness of the programme. For example, Emily comments:

> *…and in fact perhaps the programme works its way in ways that one isn't even thinking that it's working, in which case it's really working isn't it*? (458)

This was not the experience of all participants as some struggled to make time to practise, choosing to do other things and realising that there was a need to be disciplined to a certain extent to get benefit from the programme. Yet practising enabled participants to prioritise time for themselves. Generally, to practise, participants need to take themselves away on their own and as Olivia explains

> *…it makes you take some time out for yourself, you know, you go into a quiet room and just sort of separated yourself from the rest of the family and everything like that, so taking time for yourself*" (40).

Tangible benefits reported included feeling calmer and more able to cope with what was thrown at participants. Some of the practices became a resource to help calm participants when they were feeling irritated by their Caree. In this sense the practices were seen as instrumental tools, techniques and mechanisms (Olivia and Sophie specifically refer to this) rather than part of a philosophy of self-compassion.

Despite the participants' general positivity about iCare and the impact it had had, only Olivia, Tamsin and Isabel were explicit that either they had or intended to maintain their practice of the formal and informal practices post iCare. Others, such as Karen and Beth, said that they had been too busy to practise since the end of the programme. Karen added that she had not felt the need, implying that the practices are seen as a response to difficulty rather than a 'mind and heart' training to be maintained for the rest of life:

I have had peculiarly busy 2 or 3 weeks recently so I would be less likely to have done them anyway and because I wasn't feeling the need like a desperate need either then I haven't chosen to do that. (100)

Beth did say she would carry on listening to the second CD as there were some meditations she had not listened to by the time of interview, but it appeared as if this was curiosity rather than a desire to engage with the material.

It would be misleading to give the impression that iCare came easily and without difficulty to all participants. Some of the difficulties are explored below where responses to the individual practices are discussed. Generally, the participants did not specifically highlight many of the practices for further comment. The **Body Scan** is the first formal meditation that participants are introduced to. Other than Sophie who had enjoyed this practice from the start it was not singled out positively by other participants. Dawn had a negative reaction to it as she was uncomfortable with focusing on various parts of her body and found it "*a bit weird*" (222). **Soothing Touch** is an informal practice introduced early on in the programme, but it does involve intentional physical contact with the body with the aim of self-soothing. This was not always successful in the way it was originally offered. For example, similar to the Body Scan, Dawn disliked this practice giving the reason that "*there's not a lot of physical contact in my life*" (118) and she was uncomfortable with the focus on touch, but she then adapted the practice into what we referred to as 'canine soothing touch' involving close contact with her dogs.

As the intent behind Soothing Touch is to help participants identify a self-soothing practice, this worked for her as did Linda's discovery in-between iCare sessions that despite not finding any soothing physical touch, her self-soothing came via the nose, inhaling aromatherapy oils or plants such as lavender and rosemary. Beth explained during her interview that she did not like being touched but she was prepared to try the practice and reported:

Well, I did that thing with the heart thing didn't I, I've done that a few times, especially if my heart feels like it's racing or something like that, and I try and

calm down and breathe a bit more, you know, try and think of something nice,[laughs] (49)

Olivia liked this practice as did Emily although she was a little shy, only using it when she felt she was not being watched but recognising how easy it was to incorporate into life.

The second formal meditation is **Affectionate Breathing,** which was included on the first CD given to participants in both a longer and shorter version together with five-minute breath and sound meditations. Whilst general references to breath meditations are made by participants and 'shorter' practices, no specific mention was made of this practice. **The Pause** is a very brief practice of taking one to three deep intentional breaths as a way of grounding the individual in the present and slowing thought patterns and emotional responses; this appeared to be popular. Dawn said she found it useful, and it helped Olivia "*to catch your breath and …erm, take stock a little bit*" (37) and for Beth it seemed like it was the main practice she used:

I do use the Pause, it's like when I'm doing something, he's asked me to do something, I've gone back and he's shouted me again to do something, and then I kind of like do a pause, and then he said 'will you do me meds?', just as I, oh…so I went back again, it's like taking a breath backwards, you know [laughs] (73)

CD 2 contained self-compassion-oriented practices and a Gratitude practice. Included is a practice particularly aimed at Carers, the **Caregiver's Practice.** Sophie rated this as one of her favourite practices and Olivia made a specific reference to it. When asked how Carers could be encouraged to look after themselves, her response was essentially a summary of this practice:

I suppose to, to remind them that it's their life too, you know erm, you know, we only have one life and whilst, you know, caring for somebody is sort of

admirable, something you have to do, erm, erm, it's, it's their life too, you know, (256)

For Tamsin, this practice unlocked repressed feelings built up over the years of caring for her wife and the more she practised it the more feelings poured out:

It's like its got more and more effective if that makes sense, as in, I'm not holding back, it feels like more's coming out, so now she'll say 'I'm going for a cigarette after this is finished' and I'm like 'okay', 'are you coming?', 'no' and then I've got more time to let it out if that makes sense, rather than be distracted from what I've been thinking and then holding it going 'no I'm fine' and then kind of, letting it out, (8)

It is unclear why a practice aimed specifically at Carers was not more widely used by the other participants, but perhaps Tamsin's experience illustrates the depth of feelings contained by Carers and thus for some there may be a reluctance to open to these feelings or participants may be choosing to close down and not allow deep, painful feelings through which could be a wise, pragmatic choice.

Loving-Kindness meditation is a Buddhist practice, also known as *Metta*, a Pali word which is usually translated as 'loving-kindness' and involves generating feelings of friendship and kindliness to yourself, and then to others in an extended version. It uses a particular grammatical style, the optative mood which uses the words 'May I …'. CD2 contains a version of Loving-Kindness tailored toward self-kindness and meeting some of your needs in difficult times. The title 'Loving-Kindness' left some participants a little uncomfortable, but others referred to the value of this practice. Olivia mentioned the positivity of "*wishing yourself well isn't it really, wishing good things for yourself, you know, have the strength to cope with what's coming next, you know that type of thing*" (68).

Tamsin interpreted the practice in a different way finding the use of the phrase 'may I …' gave her permission, flexibility and possibility to make self-caring choices and she

often referred to how she would ask herself 'may I …' , rather than practising in a formal manner.

The **Gratitude** practice was appreciated by some for its positive nature. Sophie found it a powerful and supportive practice explaining that as she was not too keen on 'suffering' this offset some of the focus on the difficulties of being a Carer:

> *… 'cos it's that half… it's that glass half full, isn't it? Even when things are really bad, and the thing is you are caring for a loved one. You're lucky you've got a loved one and everything that's happened between them it's… you know, it's just switching your mind set a little bit, isn't it? (286)*

The positivity was echoed by both Olivia and Linda as something they had particularly taken from iCare, whereas Tamsin found it took much longer for her to get into the practice and in her interview her focus was much more on the permission giving nature of the programme rather than exploring things to be grateful for.

<u>Sub-theme: Absorbing Theory by Osmosis</u>

This sub-theme addresses how participants make sense of and soak up the theory underpinning iCare, which is based on the work of Neff and Germer (2013) which, in turn, utilises Neff's definition of self-compassion (Neff, 2003b). As a reminder this encompasses three aspects: self-kindness not self-criticism, common humanity not isolation and mindfulness rather than over-identification.

In general participants do not name the theoretical concepts, other than self-compassion, that are discussed (albeit lightly) during iCare. However, it was interesting to see their language reflected some of these concepts, apparently without recognition and it appears that there was an unconscious assimilation of theory shown through the participants' own words. Linda seems to point to this osmotic absorption when she says, "*And I think once you keep listening and keep trying, it does sort of go in" (72).*

Self-Compassion

There were a variety of definitions offered by participants as to what self-compassion meant to them. Olivia saw it as meaning "*to be compassionate towards yourself and to be kind towards yourself*" (244), whereas Isabel highlighted that the starting point was about self-awareness and self-respect. Dawn too mentions self-awareness as the starting point for developing self-compassion. It seems that Dawn and Isabel are pointing towards Neff's definition of self-compassion which postulates that the starting point is awareness (mindfulness) - you have to be aware of your pain and suffering first before you offer yourself kindness. Emily certainly reflects this definition when she says self-compassion is "*I think being mindful of, of what is, is really in there that's causing distress or a measure of upset*" (226) before adding that it also included acknowledging pain "*and actually try and nurture a form of …I don't know if healing is the right word, but but sort of soothing*" (230).

Sophie defined self-compassion as self-love and *"it's all about like being your best friend, isn't it?*" (156). Finally Tamsin offers a song, Save Myself (Sheeran & Wadge, 2017), as her definition of self-compassion, which is similar to Sophie's given its theme of loving yourself:

> *there's a song…Ed Sheeran*[2] *I think, I've got to learn to love myself before I can love anyone else or something like that, and it's been quite nice just doing that and not feeling bad, just thinking this is what… not normal people, but this is what people that are self-compassionate do* (220)

Sophie is the only participant to raise the opinion that self-compassion could be seen by others as 'airy-fairy' and that, at times, she felt obliged to defend it; at least at the beginning before it became more natural and embedded. She gained credibility from Professor Paul Gilbert's work on compassion focussed therapy (Gilbert, 2010a, 2010b) as "*It was only when I saw um Paul Gilbert talking and I realised, oh, you know, he's credible, very credible*" (170).

[2] Her wife was a great fan

Mindfulness/awareness There are many definitions of mindfulness but in this study the following definition is being used: *"(1) awareness, (2) of present experience, (3) with acceptance"* (Germer, 2005, p. 7). Participants may not have used the term 'mindfulness' or 'mindfully' often, but they frequently referred to mindful moments or approaching life mindfully (without the mindful label) and were able to identify when either they or others were not being mindful, often around dwelling on the past or worrying about the future.

As discussed previously, Beth did not find the practices contained within iCare easy to follow, nor did she seem greatly taken with the theoretical concepts the programme referred to. Yet she offered several examples of mindfulness and awareness in action, best summed up by this quotation:

> *you shoot forward and you think 'oh god, what's going to happen next?, this bed's coming, this is going to happen' you're there before it's happened, [laughs]* (269)

where she can see what her mind wants to do, rush forward into the (negative) future rather than stay in the present where her husband still retains some functionality. Linda reminded her father to "*live for the now*" (30) rather than dwell on how her ex-husband had treated her. When it came to her mother's illness she emphasised "*we just need to enjoy now, let's do what we can do now*" (164), rather than fret about the future. Isabel referred to her awareness that she needed to pay attention to herself closely "*you just have to be mindful about it*" (58) to avoid burn out.

Sophie offers a good example of over-identification as opposed to mindfulness when she says:

> *I stuff it or I get stuck in it and then I feel miserable and I get stuck in it. Oh, it's all horrible. It's so miserable. There's no end to this, you know, for Mum, and it's all downhill for Mum, blah, blah, blah* (384)

She recognises her downward spiral into negativity before she allows herself to accept the situation with her mother rather than resisting it, which then allows the feelings to lose intensity and she has space to focus more on the positive. Sophie also offers her own definition of mindfulness, which is more:

> *about appreciating, isn't it, it's what ultimately it's about, appreciating all the little things every day* (280)

Mindfulness incorporates acceptance in the sense of allowing things to be as they are, both enjoyable and uncomfortable, once we are aware of them. Linda gives an example of this when she accepts that she cannot change a situation so there is little point in getting anxious about it and there is always the possibility that tomorrow might be better. She talks about *"the willingness to accept as well what's happening"* (158) and the permission to be just as you are:

> *that it's okay to feel how I feel. Whether it's feeling miserable, whether it's feeling happy, whether it's irritable, any of those things it's okay because it's it's that moment and then you go on from there to feel better*" (136)

Emily also began to reach a place of acceptance with her situation saying, "*I think I've realised that that's the way it is"* (26).

Contrary to acceptance is resisting what is. In her mother's care home Sophie could see that whilst she could handle the behaviour of the other residents, with her mother she was frustrated that she found it harder to accept how she was *"Come on Mum get a grip, you know. [Laughs]"* (212). Yet she then went on to describe how she was able to fully accept her mother eating a crumpet out in public in a way that previously she would have struggled to accept. For Tamsin, deeply held feelings had been resisted for many years, but she described how she allowed herself to feel and touch these feelings which seemed healing for her. Dawn acknowledged that she was clearly resisting exploring

deeper feelings, but this was done from a position of knowledge and choice. She did not want to lose what she considered to be recently acquired control,

> *a feeling of not wanting to go deeper because I don't know what I might find out, and because I now feel in control I don't want to risk that control…* (54).

This may be about trusting herself to only go as far as she felt appropriate within the parameters of both the programme and her caring situation. This can be seen as a self-compassionate act in itself.

Common Humanity Whilst Sophie admitted that she struggled with accepting 'common humanity' (she did not want to be reminded of all the suffering in the world) she did have a profound moment of sensing into connection and equality with others:

> *I really felt that we're all equal and I am equal to everybody in that home, even if they can't move or speak or at the very end of dementia, we're equal (200)*

Whilst earlier in her interview there was a cognitive resistance to the concept, as she talked it was apparent that she had an experiential understanding of it.

Others could see that they were not on their own struggling being a Carer. For example, Beth comments "*I mean things like you say, have happened to other people haven't they?*" (197) and Olivia adds *"it is hard but there are other people going through this sort of stuff as well*" (40) both of which point to the commonality of human suffering.

Wise Compassion Whilst wise compassion does not explicitly form part of Neff's definition of self-compassion, iCare does address that being compassionate towards yourself does not mean becoming self-indulgent and that sometimes, difficult decisions have to be taken in order to be kind to yourself (e.g. exercising when you don't feel like it but when it is in your best interests or saying 'Stop' to abusive behaviour). Hence, there is a wisdom to self-compassion which is often referred to as 'wise' compassion. Beth and Sophie are the only two participants to make oblique references to this. Given

Sophie's reading around the subject she may have felt more comfortable with the idea of 'wise compassion' as her definition of self-compassion includes clear references to it:

> *it's not sort of letting yourself get away with anything, sort of thing, you know. It's also, you know, giving yourself a gentle nudge and things like that, isn't it?* (156).

Beth sees the wisdom aspect of self-compassion (without naming it) as recognising your patterns which necessitates a pushing through your own resistance *"…push through the barrier don't you really? …Otherwise you get just in a rut again, you just stay at home again"* (157-161). Participants expressed theoretical concepts without particularly recognising that they were doing so. iCare does not foreground theory yet it is apparent that participants have absorbed some concepts without being consciously aware of this.

Sub-theme: Evaluating iCare - Gains and Pains

Participants had many reflections and thoughts about iCare after they had completed it including positives and drawbacks. They named emotional and cognitive changes and as seen earlier participants described behavioural changes in the way they practised self-care.

Dawn described how following iCare she was able to stop herself getting so wound up by her father by stepping back and gaining perspective. She accepted that there would always be triggers, which could annoy her, but that now she was less likely to remain irritated. There is some realism in recognising that irritation was going to happen from time to time, but that either she would come down more quickly from a heightened state of arousal, or that she would be less likely to act on the irritability she may be experiencing:

> *I can't say my feelings of wanting to strangle people have gone away altogether, [laughs] because then that just wouldn't be me, [laughs] erm, should we say I feel less inclined to act upon them now than I usually do. [Laughs]* (Dawn,158)

A sense of coping or feeling more in control was echoed by several participants, which was attributed by them to iCare. Participants talked about a sense of calm, *"I'm generally more calm"* (Emily, 18), or being able to remain calm when responding to a demanding or upset Caree or indeed others outside the caring relationship. Linda noticed her ability to stay calm when being harangued by her divorcing husband and her ability to detach and control her response to him *"I didn't let him wind me up and make me feel bad so that was really good*" (30).

Changes in thinking were described by some of the participants, such as Linda, who seemed to become more aware of her negative thinking and then made a determined effort to practise acceptance of what is and, as a result, reduce her anxiety:

> *there is nothing that I can change about it so let it ride and not get so anxious about it because tomorrow it might be better* (20).

Beth noticed that as she became more positive in outlook she felt able to do more "*the more I think positive, the more I do things*" (269). Tamsin talked about becoming more independent in her thinking, that she could trust herself more and rely less on guidance and advice from her wife as she analysed situations:

> *instead of like saying to [wife] 'I'm not happy on this ward' or worrying [wife] I just thought well I'll just face it, if I'm not happy or if I'm not happy with my patients I'll just report it (160)*

Participants reflected on the value of iCare to themselves and to other Carers, generally enjoying the programme and gaining new ideas and appreciating the shifts that had been achieved. Beth struggled with the concept of iCare and found the meditations difficult and, whilst changes were evident in both her thinking and what she was physically doing to take care of herself, she didn't offer a strong endorsement of iCare other than "*it's been good though, it's good*" (241). Beth saw the benefits coming from getting out and talking to someone not the practices or concepts. The other participants were more positive, to varying degrees, about the value of iCare. Karen found it

"*enjoyable and pleasurable*" (144) and was wistful about the end of the programme "*I will be always thinking 'oh it's finished', you know, I have got that sort of feeling of 'oh it's all finished'*" (246). Sophie also "*really enjoyed it*" (422) and found it "*lovely…really, really nice*" (424) and because of her experience wanted to spread the word about iCare to fellow carers in her mother's nursing home. Olivia had been telling her friends about it and would "*definitely recommend it to anybody"* (76). Linda endorsed its value to other Carers and a further recommendation also came from Isabel who linked iCare to Carer sustainability:

> *I would definitely recommend it and I would say that in order for them to sustain their care for their patient they need to sustain their own self-compassion and work on themselves first (82).*

Dawn was surprised that she got something out of mindfulness "*wouldn't have thought …that I was necessarily the sort of person that would get anything out of it; this airy-fairy mindfulness stuff,* [laughs]" (138), whilst Emily was enthusiastic about the programme. She found it useful and beneficial, seeing it as a positive experience and something which had "*been very good, I feel it's been an enormous help in me coping now and in the future"* (482). Olivia also commented on taking something into the future from the programme *"I've gained an awful lot from it and got some really good things for, err, going forward*" (332). Tamsin commented on how helpful the programme had been expressing her gratitude:

> *thank you for letting me be a part of it, it really has changed me but in a better way, I can see that and if [wife] can see it then I know that it's working* (432).

Linda felt that iCare had made her feel better and so "*for me every bit of it, it was worth coming and it was worth just listening and then doing all the practices*" (154). Beth saw iCare as less of a programme offering tools and psychoeducation but more of an opportunity to get out and talk to someone:

it's got me out of, a little bit of a break, and I can speak and it's not just [husband] I'm speaking to, you know, it's somebody different (241).

For her this was the value of the programme, a place to talk which wasn't counselling, of which she had had some negative experiences.

As part of evaluating iCare participants also reflected on what had not worked as well or what was less enjoyable. When asked what they had found difficult or which elements of the programme had not resonated, participants were generally positive. Difficulties experienced were with the short structure of the course, the challenges of balancing participation with the Caree's needs and on occasions how participants stopped themselves from benefitting fully from the programme. As seen earlier not all practices resonated with participants. As they were encouraged to pick and choose practices, trusting themselves to be guided by what they felt they needed, participants appeared to be comfortable with the course content as they knew there was no right or wrong way to approach iCare, only their way.

Some participants faced practical challenges to implementing iCare in their daily lives**.** Those living with their Caree reported that they were often disturbed when practising by their Caree calling for something. Karen found that if she played one of the CDs in another room from her husband, he would call thinking she was on the telephone and wondering who she was speaking to. To avoid having to start again each time she listened to the CD, Karen took to playing it with her husband. Emily chose to only practise the shorter meditations for similar reasons – anticipating being interrupted. The shorter the practice the less likely the interruption. This meant she missed out on some of the lengthier practices, but she hoped that one day if her husband went to day care at a local hospice this might provide an opportunity for her to explore them. She uses the words "*feel confident*" (106) that at those times she won't be interrupted. This may speak to the life of Carers: always listening out just in case they might be needed and the only possibility for relaxing and not fearing being disturbed is when they are apart, often only when the Caree is being safely cared for elsewhere. Olivia speaks to the predicament Carers face – she chose at times to prioritise her husband "*if [husband] says*

he wants something, I'll, I'll run off and go and do it" (116). Carers tend to put the Caree's needs first and whilst iCare encouraged Carers to remember that they had needs too, this is a difficult mindset to let go of and can present as a moral dilemma.

Structurally participants either thought iCare was too short or they wanted iCare to continue beyond the four-session format with further engagement and support. Although commenting about the delivery of iCare online, Isabel's thoughts seem pertinent to the course structure in general. She questioned:

> *whether the four weeks will be long enough for some people to get into those, that space 'cos for a lot of people it might be too quick and they might then feel cast adrift at the end of it* (249)

Sophie also questioned whether four weeks was long enough and, like Isabel, she reflected on the abruptness of the ending "*four weeks is quite intense and then nothing*" (88 2). To ease this abruptness, she suggested either spreading out sessions, so they were less frequent than weekly or that there was the offer of subsequent follow-up sessions at monthly intervals for two months. The personal connection with me was important as she added:

> *It would be nice to see you again, after the four-week course, to share progress and help keep us motivated* (P88 7)

Karen also wanted more sessions "*It could have been quite good if I had some more sessions*" (246).

Participants were asked whether anything got in the way of them being more kind or self-compassionate to themselves. The most common response was 'me'. Dawn and Emily saw early conditioning as a barrier at least initially.

> *I've always been, and was brought up to be self-critical, and I'm 50 for goodness sake, it's difficult to let that go. [Laughs]* (Dawn, 305)

Dawn could see that as a result she stood in her own way. Emily too saw that she was her barrier *"me, me, it's accepting …to put myself as an importance*" (382-390) which she said arose from her childhood. Beth was aware of her vulnerability arising from her past experiences and to protect herself put a barrier up "*I've been hurt that many times that I don't want to put that barrier down*" (41) which made it difficult for her to access her own kindly feelings towards herself although behaviourally she was able to take more care of herself.

Whilst other participants were clear that nothing had particularly stopped them from becoming more self-compassionate Olivia did refer to needing permission first "*no, now that I know it's okay to do it*" (240).

5.3.4 Theme: In the Trenches

Participants were not asked directly about their experiences of being a Carer but it was possible to detect some of the challenges of caring for those with a life-limiting diagnosis within the participants' reflections on iCare. These were important to capture as they help to situate participants within their caring role which thus impacts on their ability to engage with iCare. To fail to consider the realities of caring felt unethical and in holding the principles of trustworthiness and respect for the participants (British Association for Counselling and Psychotherapy, 2019) it was considered important to do so. **In the Trenches** captures the participants' experiences of being a Carer, of being conscripted in a 'war' not of their choosing, facing the challenges of managing the physical demands of caring and the responsibility for providing protection and comfort to a fatally injured 'comrade' (loved one).

This theme points to the long drawn out struggle that Carers are generally involved in punctuated by moments of intense combat (e.g. sudden changes in the Caree's health or battles with bureaucracy and/or the medical professionals when treatment options run out or pain relief fails to work). Not dissimilar to the soldiers of the First World War ensconced in their trenches for a long war of attrition, Carers are potentially exposed to long-lasting effects of stress including post-traumatic stress (caring for a Caree can be

traumatic and the impact last long into bereavement) and emotional and/or physical burnout.

Sub-theme: Soldiering On

This sub-theme addresses the sense of participants as weary foot soldiers in a war of attrition against the enemy, terminal illness, coping with the day to day struggles as they march forward. Frustrations were inherent to their caring role. Karen expressed her frustration with her husband who, at times, could become irritable, accusing her of treating him "*like a naughty schoolboy*" (48), something which she vehemently denied but, at the same time, recognised that she had to contain her feelings and not react to avoid an escalation. An irritable Caree was not unknown to Dawn who described her father at times being "*generally arsey*" (38) and she could get irritated with what she saw as the ridiculousness of his comments. Some participants were wearied by their Caree's demands e.g. for assistance, drinks, medication, or from the Caree's irascibility and yet, despite this, Carers willingly supported and cared for their Caree demonstrating patience and understanding.

There is a sense for some that time is not their own and that even when away from their Caree the need to get back on duty loomed. Tamsin worried about getting back to her wife when out of the home, and when she wasn't working "*it would always be all my time would be concentrating on* [wife]" (204). Beth gives an example of being at her husband's beck and call:

> *it's like when I'm doing something, he's asked me to do something, I've gone back and he's shouted me again to do something … so you have to do, don't you, you have to laugh like that and get through it kind of thing… you try and get on with something and he's stopped you and you've interrupted again* (73).

For Beth, she 'gets through' this with laughter but it's unclear how genuine this laughter is; there seems to be an implicit sad resignation of their situation. Meeting a Caree's needs never stops and, as Beth points out, all these small moments of helping (which are interruptions to your own life) add up. Time away from the Caree to give the

participant a break was difficult to achieve but valued by participants. Karen recognised she was lucky that she could still have breaks, or it felt like a break if her husband went to the library and she had some alone time in the house. Olivia named getting a break as important too, "*getting time away*" (264), even if that only meant having a walk around the block or in Beth's case going to the shops to get out as "*you need to get out of that environment*" (121).

A Carer's life if often piecemeal and this is reflected in Olivia's account of caring when she says:

> *I operate in a very fragmented way now, I don't, I don't make time to sit down and read or to finish a job, because he's interrupted me so I'm not sort of sorting the paperwork; if he's interrupted me I'll do what he does, and then I'll go off and do something else,…* (116)

As seen earlier, the frequent interruptions in a Carer's life makes the shorter practices attractive to Carers as there is less chance of being disturbed, but still Carers live with the awareness that they may be called for at any time "*I think I'm always prepared for that*" (Emily, 26).

Whilst participants faced these frustrations, only Olivia admitted that she struggled to ask for help for herself. Olivia knew that she had friends who were there for her, but it was "*very difficult, very hard to ask them to do anything for me*" (56). Other participants did not address this, either because they had little difficulty in seeking support, or more likely, given Carers' general reluctance to seek help for themselves, they did not even consider asking for assistance. As their Caree's health deteriorated though, Beth and Emily commented on the future necessity of having to accept help from outside agencies. Whilst this was essential for their Caree, this would come at a cost such as lack of privacy for both Caree and participant and would signal a downward change in the health of their Caree.

Sub-theme: The Wounds of War

Caring for someone important to you who has a life-limiting illness generally inflicts injuries, sometimes physical such as stress and exhaustion leading to the Carer's own health issues, or mental and emotional such as depression, anxiety and anticipatory grief. iCare was created to help address some of these 'injuries' and to support Carers in what is often a 'war of attrition'. The participants were not directly asked about the pain they experience as a result of caring. Yet, for some, their words were imbued with a quiet pain and loss. This reflects the Carer's lot; a life now lived with grief and sadness infused with stoicism. The participants felt comfortable sharing their painful reality with me despite this not being the focus of iCare sessions or the research interview, perhaps as a result of the *compassionate presence* offered, sensing a genuine interest in them, a rare experience perhaps?

Participants talked about containing and stuffing their emotions. Tamsin referred to being brave by holding her feelings in and knew she was protecting her Caree *"I'm worried about crying in front of her in case she feels even more guilty than she does for being ill*" (8). but for others, such as Beth, there was a recognition that there was a limit to what can be contained:

> *it was getting too bottled up in here; it would either come out in just saying things fast or what have you, or I could just explode somewhere you know, and I didn't want to do that and have a breakdown or something* (173)

It is deeply distressing to witness someone you love ebb away bit by bit whether that is physically and/or cognitively. Olivia puts this as the price you must pay for love:

> *One of the reasons I feel so sad watching the Mum I knew slip away as a result of dementia, is because I love her so much. Thinking of it like that, comforts me* (88 34).

Emily pointed to the minute changes in her husband's ability to do things, indicating a downward trajectory in his function. Tamsin witnessed her wife's anger at the lack of treatment options and the blunt way she was treated by doctors:

> *it looked like she was pregnant but she was never going to have a baby, that's what she said to [wife], that was it, … and it says that the abdomen tumour was enormous, this is what she had written in the letter, and that radiology was just a case of hope over science* (28)

Understandably she was angry and distressed on her wife's behalf who then lost hope and became really upset:

> *like 'why am I bothering, is there a point in me doing it, why am I making myself ill if the doctor doesn't think it's going to work?'*

For Tamsin though, accepting the inevitable and facing what was coming allowed her to tackle some of the organisational issues she had been putting off such as identifying undertakers. Yet there was a sadness inherent in her description of the television programme they had watched which elicited a conversation about future relationships after her wife's death:

> *like I know I'm not 40 yet and there may be another relationship if it happens in the future, but I'm not going out intentionally to look for that when [wife] has gone, but watching it just made me think I'd rather sit at home with a hot water bottle and a cup of tea* (400)

Pain experienced through caring may not just be related to current caring. For Isabel unanticipated pain came from reliving memories of a previous caring episode triggered by her present caring responsibilities which "*brought back a lot of stuff for me really…that was a bit of a wobble that I couldn't have foreseen*" (119).

The wounds that are inflicted on Carers are many: a terminal diagnosis fractures the assumptive world of both Carer and Caree. There may be the loss of conversational intimacy with a loved one that happens when Carees can no longer initiate conversation either through cognitive decline or physical weakness. For couples, the social life that they may have had disappears "*there's no point buying fancy dresses 'cos you're not going anywhere to wear a fancy dress*" (Olivia, 276). Olivia talks wistfully about the spontaneous lives of couple friends:

> *we've been away for the weekend you know, with friends you know, and in another life I'd have been doing what they're doing, like going on holiday all the time, or you know erm, going out for more meals* (312).

It can be hard for Carers, particularly those living with their Caree, to see themselves as anything other than a carer which Olivia addresses "*you tend to lose a bit of your identity a bit really"* (276).

Physical disability of the Caree can mean that normal joint activities stop; Emily comments:

> *in the past* [husband] *and I would have gone to something like that together but unless they've changed,* [venue]*...has not become terrible disabled friendly because of the way it was built* (46).

Carers may need to remain patient as the Caree adjusts (if ever) to their physical limitations and accept, for example, mobility aids/vehicles to enable journeys outside the home. Adjustments to plans have to be accommodated as Carees suddenly deteriorate and longed for concert going has to be forgone or travel arrangements have to be planned in minute detail to meet the Caree's needs. Emily and Tamsin both gave examples of these situations.

Emily raised the potential impact of caring on a Carer's career. She recognised that she was lucky that she was already scaling back her consultancy business when her husband

was diagnosed which allowed her to assume her caring role. As she says, if she had been five to ten years younger and under pressure to earn then her situation would have been much more challenging. Other participants' working lives were affected by their caring role. Tamsin negotiated her shifts around meeting her Caree's needs and both Beth and Dawn had given up or taken breaks from their jobs whilst Olivia had resigned from a much-valued volunteering position to devote more time to her caring responsibilities. Carers may face losses of career, educational, family or social opportunities but this may be especially relevant for younger Carers who have active careers or who like Tamsin has probably lost the opportunity to have children as her life became about caring for her wife *"I've always been broody, I've always wanted them, we've talked about it*, [wife] *didn't, I did, we then talked about doing it but then obviously she became poorly again"* (412)

Socially the life of the Carer is impacted; the freedom to do things you have always done drops away. No longer are long solo day trips or overnight stays away from home achieved without great planning and the support of friends and family, if a Carer is lucky enough to have that support "*the opportunity to spend a day with one of my specific activities in London is out*" (Emily, 48). Social isolation was mentioned by several Carers and also the fear of boring (and presumably potentially losing) the friends you do have by talking about your Caree, their illness and yourself as Carer. Yet the effort involved in socialising, especially if feeling emotionally low, can mean that Carers would rather stay at home:

> *if the girls want to go out, I can't be bothered; I've got that much going on anyhow, do I really want to …put…you know, it's like another do it, it shouldn't be it should it, it's like something else you've got to do, whereas you just think 'oh , I'll just sit down, I can't be bothered'* (Beth, 153)

Sub-theme: Line of Duty

This sub-theme attempts to capture the obligations and sense of duty that Carers assumed in their caring role. Carers are generally always on duty even when stepping away from responsibilities for a brief period. As conscientious soldiers Carers need to

be fit and well to maintain their caring role. Some saw this as quite onerous particularly in the face of their own ill-health, "*gosh this is putting an awful strain on me to be fit and healthy*" (Karen 156) or as Olivia said, "*it just puts enormous strain on you to look after yourself* (160). Interestingly, both participants use the word 'strain' with the tension and heaviness that that word conjures. The moral responsibility to stay well is further described by Olivia as a duty "*you've got a duty to look after yourself haven't you*" (260) which adds to the sense of pressure. Keeping well was also seen as encompassing mental and emotional wellness - perhaps the motivation for participating in iCare for some participants.

As Carers, the participants remain focussed on how to make their Caree's life easier. This can involve such things as encouraging social interaction or organising more appropriate equipment and nursing facilities at home. The participants saw themselves as the Caree's advocate, perhaps setting boundaries with third parties, taking responsibility for organising the Caree's care or arguing for better care in a sometimes-unhelpful health and social care system. The Caree was always put first "*all the focus was on Mum and doing things*" (Linda, 52). Sophie is the only participant to be explicit about the need to act in an ethical manner in the line of duty as a Carer; she was aware that to a certain extent she had power over her mother:

> *it's a very, um, have to be careful not to use my power. Only use it when I want to help Mum, you know, um protect her, sort of thing. Not in a harmful way for her.* (198).

Olivia is mindful about remembering the person beyond the diagnosis, part of the Carer's duty, "*there's still an intelligent person underneath that, the illness*" (308).

Whilst participants may know that they are doing what they should be doing at this time in their life in looking after their Caree, Olivia does use the word 'should', "*I know I'm doing what I should be doing now*" (272) hinting at an implicit *duty* to care. Other participants are silent on this point; the provision of care is not questioned, presumably

having absorbed societal expectations and assumptions of a duty to care without question.

5.4 Quantitative Analysis - Descriptive Statistics

Table 7 presents the results of the scores for the SCS and DASS self-report instruments for Phase One of the study setting out the comparisons of pre- and post-intervention scores, significance and percentage changes in scores. In order to interpret these results Neff offers some guidance regarding interpreting self-compassion scores (Neff, 2003a, 2020b) and suggests that a mean score of around 3.0 represents an average score for self-compassion with a score of 1-2.5 representing low self-compassion, 2.5-3.5 moderate levels of self-compassion and 3.5 to 5.0 high levels of self-compassion. Higher scores for the Self-Judgment, Isolation, and Over-Identification subscales indicate lower levels of self-compassion, while lower scores on these subscales denote greater self-compassion. Table 8 details the severity ratings for DASS as indicated by Lovibond and Lovibond (1995) to facilitate ease of review of the results.

Table 7

Phase One Pre- and Post-iCare Scores Analysed with Paired Samples t-tests

Measure	**n= 9**	**Pre-test M (SD)**	**Post M (SD)**	**Mean Difference**	**% change**	**p-value***	**95% CI**
Self-Compassion Scale (SCS) Total	9	2.99 (0.93)	3.28 (0.97)	-0.29	9.70	.29	[-0.89 to 0.31]
Self-Kindness	9	2.47 (1.20)	3.36 (1.20)	-0.89	36.03	.02	[-1.60 to -0.17]
Self-Judgement #	9	3.04 (1.16)	2.73 (1.00)	0.31	-10.20	.40	[-0.50 to 1.12]
Common Humanity	9	2.72 (1.37)	3.17 (1.43)	-0.44	16.54	.28	[-1.32 to 0.43]
Isolation #	9	2.86 (1.16)	2.67 (0.85)	0.19	-6.64	.61	[-0.64 to 1.02]
Mindfulness	9	3.03 (1.05)	3.42 (0.77)	-0.39	12.87	.12	[-0.90 to 0.12]
Over-Identification #	9	2.75 (1.00)	2.42 (0.82)	0.33	-12.00	.30	[-0.36 to 1.02]
Depression, Anxiety, Stress Scales (DASS)							
Depression	9	16.33 (9.38)	8.56 (6.23)	7.78	-47.58	.032	[0.85 to 14.70]
Anxiety	9	8.89 (8.78)	4.67 (5.59)	4.22	-47.47	.301	[-4.58 to 13.03]
Stress	9	23.22 (11.17)	12.33 (6.63)	10.89	-46.90	.022	[2.03 to 19.75]

Note. Shading represents measure showing significance; # item is reverse scored, lower scores indicating lower levels of the negative sub-scales of the SCS; M = mean; SD = standard deviation; CI = confidence interval; *= significance level $p \leq 0.05$

Table 8

DASS Severity Ratings

DASS (42) Scoring	Depression	Anxiety	Stress
Normal	0-9	0-7	0-14
Mild	10-13	8-9	15-18
Moderate	14-20	10-14	19-25
Severe	21-27	15-19	26-33
Extremely Severe	28+	20+	34+

(Lovibond & Lovibond, 1995, p. 9)

Participants reported increases in global self-compassion and significantly decreased depression and stress scores following completion of iCare. Pre-iCare total SCS scores were below average based on Neff's guidelines and scores moved into the average range post iCare. Anxiety scores noticeably decreased but statistical significance was not reached. The separate analysis of the SCS subscales indicated post-iCare increases in the positive subscales of the SCS and reductions in the negative subscales. Of note is the statistically significant increase in Self-Kindness which moved from the 'low' self-compassion category into the 'moderate' category with a 36.03% increase in scores. The participants' scores for DASS pre-iCare indicated that they fell into the Moderate categories for Depression and Stress and Mild category for Anxiety. After completing iCare participants' scores had moved into the Normal category across all three dimensions.

5.5 Brief Discussion - Bridging Phase One and Phase Two

Phase One of the study aimed to provide an evidence base for the acceptability of the content of iCare as a brief self-compassion programme tailored for Carers and to gain participants' views about how to deliver such a programme online. This section briefly reviews the finding from Phase One of the study as they relate to the refinement and design of the intervention to be used as the basis for Phase Two (the online

intervention). A fuller discussion of the findings from Phase One including relating them to current literature will be found in Chapter Eight.

In general participants considered the face to face iCare programme to be valuable. It lead to several personal insights, a kinder way of relating to themselves expressed through behavioural and cognitive changes and confidence in using a number of tools (by way of meditations or in the moment practices) to support themselves in the Carer role. The qualitative findings were supported by the quantitative findings which showed positive increases in self-compassion and reductions in depression, anxiety and stress following completion of iCare.

The structure of the programme seemed to be acceptable to participants although there was some concern that it ended abruptly and may be too short in duration for some. Overall, there did not appear to be any support for major changes to be made to the structure or content of the iCare programme before it was moved online. In order to replicate online the positive aspects of the programme the following attenuated points arising from the findings of Phase One were considered in the refinement and development of the online version of iCare:

- The value of emphasising a kindlier way of talking to oneself
- The need to develop a 'compassionate presence' in all material
- Ensuring meditations/practices were generally shorter in length
- The need to remind participants to persevere with the content as it seems to take at least to the second session for the content to begin to resonate with participants
- The importance of emphasising giving oneself permission to practise self-care/self-kindness

- Addressing concerns about the potential loss of personal connection through an online delivery, such as in efforts made to make online content and any email communication warm, authentic and compassionate

- Given the reflections on the duration of iCare allowing participants to go at their own pace without undue pressure to complete modules in a timely fashion

- Holding a constant awareness of the challenges Carers face of being '*In the trenches*' and subtly reflecting this awareness in the creation of written, audio and visual material

- Appreciating that soothing touch was not appropriate for everyone and considering other ideas of extending soothing touch to soothing activities such as using scents or stroking animals

Bearing these points in mind an online version of iCare was then developed generally echoing the content of the face to face delivery and aiming to create an attractive user-friendly online programme that would focus on the development of Carer self-compassion.

5.6 Summary

This chapter has presented both the qualitative and quantitative findings from Phase One of the study. These provide an empirical basis for the online version of iCare utilised in Phase Two of the study. In the next chapter the research method for Phase Two of the study, which explores Carers' experience of the online version of iCare, is outlined.

Chapter Six:
Research Design and Method – Phase Two

6.1 Introduction

Phase Two of this study explores the experience of participants of a brief online four module version of iCare. This intervention is based on the face-to-face version studied in Phase One but amended, as discussed in the previous chapter, to take account of participant feedback from Phase One. The online version of iCare was designed to allow Carers freedom to access the iCare intervention at a time and place of their choosing in a user-friendly format. As in the face to face version iCare-online aimed to develop a more kindly and self-compassionate self-attitude as well as teach brief mindfulness and self-compassion practices aimed at supporting Carers.

Phase Two of the study comprised a reflexive TA of data generated through:

- online and email exchanges with participants in iCare-online
- an online open-ended qualitative questionnaire exploring participants' experiences of iCare-online

together with a statistical analysis of changes in self-compassion and psychological functioning of participants through quantitative outcome measures.

As iCare-online was a novel intervention it was important that it went through a pilot test to identify any logistical difficulties and/or challenges with the programme content in order that these could be addressed before Phase Two of the study was fully implemented. The pilot test is described further below.

6.2 iCare-online Pilot

6.2.1 Pilot Recruitment and Procedure

In line with good practice, Carers were involved in the development of iCare-online through their contributions in Phase One and also through feedback on the pilot

(Ugalde et al., 2019). During January to February 2019, contacts and colleagues who were either Carers or had an interest in the Carer role were invited to participate in the pilot of iCare-online. iCare-online had two elements to be piloted. The first consisted of the online access to the Participant Information Sheet, Consent Form, and biographical information form (Appendix 10) together with outcome measures hosted on an academic survey site, Jisc Online Surveys (Jisc, 2019). The online process was designed so that participants first had to read the online Participant Information Sheet, confirm eligibility to participate in the study and then give online consent to participate in the research before they provided biographical details and completed the outcome measures. Once this element was completed participants were then sent an email containing a link and password to the iCare-online programme. The second element to be piloted was the online intervention itself, iCare-online. After all four modules of iCare-online were completed participants were emailed a new link to the Jisc survey site with an invitation to complete the post-iCare-online qualitative questionnaire and repeat the outcome measures.

Following a review of various online training platforms, the pilot of the iCare-online intervention was initially hosted on a UK based coaching and training platform (JigsawBox Limited, 2019), which I had previous experience of as a subscriber of a coaching programme. This platform allowed for the hosting of written, audio and visual material as well as permitting interactions between facilitator and participants. It was also offered on a non-chargeable basis for six months in view of my student status and the research topic.

MP3 files, MP4 files, PDFs and text where uploaded to JigsawBox. Those involved in the pilot testing were given email access details first to the online survey site to give their consent to the research (as if they were participants), complete biographical detail and complete outcome measures. Automatic email notification of completion of these steps was delivered by Jisc Online Surveys (Jisc, 2019) direct to my personal email inbox. Then an email was sent to the colleagues and contacts who had agreed to pilot the online version of iCare providing details of how to access iCare-online (on JigsawBox). Four people agreed to pilot the programme.

6.2.3 Feedback on Pilot

Feedback received raised concerns that the outcome measures as presented on Jisc (2019) were complex to negotiate, with repetition of statements and accessibility was compromised when using a mobile telephone. Unfortunately, this could not be altered as it was a built-in feature of Jisc (2019). Whilst no concerns were raised about the content of iCare-online, difficulties were experienced with the user interface with the JigsawBox platform. Videos did not load easily or quickly, and speed and accessibility were dependent upon differing web browsers and platforms (e.g. iPad, mobile telephone, desktop computer). Other concerns raised were the lack of attractiveness of the design and the difficulties experienced by some in negotiating around the programme. It was not easy to rectify these user difficulties and finally a decision was taken to find another hosting platform. After some investigation the most suitable and cost-effective option identified was to use a web designer to move iCare-online to my personal website (hosted by "Wix" 2019) and to rework the user interface. This was subject to further testing and favourable comments were received from those testing the revised version of iCare-online regarding design, content and accessibility.

The study then moved to the next phase with a full implementation of Phase Two.

6.3 Recruitment - iCare-online

As Phase Two involved the delivery of an online intervention, as opposed to a face to face intervention as in Phase One, there were not the same geographical restrictions in terms of recruitment of participants (Phase One required participants to be located within travelling distance of me). The study was advertised using Twitter, LinkedIn, Facebook, personal email and on the home page of my website (Diggory, 2019). Hospices, illness-specific health charities, carer organisations and Twitter/Facebook groups were approached together with personal contacts.

- A pinned Tweet was used on my Twitter account @iCareResearch (see Appendix 11) advertising the research. Carer organisations in the North West of England were also sent direct messages via Twitter regarding the research as well as national groups such as the Congestive Heart Failure Group and other illness

support groups together with a few direct messages to individual carers of those with dementia.

- LinkedIn recruitment comprised an update describing Phase Two of the study and posted on my profile.

- Using Hospice UK's Find a Hospice service (Hospice UK, 2019) emails were sent to a variety of hospices based initially in the North and North West of England (these regions were chosen in case hospices were interested in a formal presentation or wanted to meet me informally). These emails described the study and attached a copy of the participant information sheet (see Appendix 12), copy of the University of Chester ethical approval for the study (see Appendix Two) and a copy of the recruitment poster (see Appendix 13). Approximately 30 emails were sent between April -May 2019; where named contacts were identified emails were generally followed up by a personal telephone call to encourage a response. Responses from hospices varied, most were interested in the study and recognised the need to support Carers, but a few had more or less onerous processes to clear before recruitment would be permitted; these were complied with. Others declined to advertise the research on the basis that they already had several research projects running including ones with Carers and they did not wish to over-burden Carers. One hospice invited me to make a formal presentation to interested members of staff who could promote the research. This was well-received but ultimately did not yield any participants. Another group of hospices declined to advertise the research on the basis that NHS Ethics approval had not been received despite this not being a requirement as hospices are not NHS organisations.

- Personal email recruitment was through an email which outlined the study and contained the participant information sheet and research poster. This was forwarded to all contacts and re-forwarded by others, to their contacts. Other personal contacts who had experience of working with Carers were contacted and these ultimately were the most fruitful in generating participants.

- Several national and local charities supporting Carers of those with various illnesses, such as Huntington's disease, MND, dementia and cancer, were contacted about the study but very few responded to emails and telephone calls. A similar poor response was received to requests to post details of the research on illness and Carer specific Facebook groups with requests either ignored or declined by administrators.

- Ad hoc contacts were also made with religious and spiritual groups with interest in end of life matters, University contacts and clinical nurse specialists.

- Opportunities to speak about this Phase of the research and to advertise it through flyers were also taken at research conferences (13th Keele Counselling (Research and Practice) Conference, Keele University 2019, BACP Annual Research Conference 2019, Belfast)

As in Phase One, the main research criteria were that participants must be aged 18 or over and caring for an adult with a life-limiting or palliative diagnosis who were sufficiently fluent in English to understand the material being delivered and willing to complete a questionnaire. Interested participants contacted me using email or mobile telephone for further information.

In total, 22 expressions of interest in iCare-online were received all of whom were sent details of the research and invited to get back in contact if they wanted to proceed with participating in the research. 18 responded positively and were sent an email containing an email link to the online consent page, participant information sheet and outcome measures (these mirrored those used for the pilot; see Appendix 10). 15 Carers proceeded to complete this online stage of the research including the pre-iCare-online outcome measures. Seven participants were recruited who completed the full iCare-online programme, the pre and post outcome measures and qualitative survey; three other participants completed pre-iCare-online outcome measures and participated to varying degrees in the programme providing comments for qualitative analysis but not

proceeding to complete the full iCare-online programme and post-iCare-online outcome measures and qualitative questionnaire.

Approximately two weeks after participants completed the iCare programme they were then sent an automated email through Jisc (2019) with password protected log in details to the qualitative questionnaire and the follow-up outcome measures.

6.3.1 Response to Recruitment Activities

Participants were recruited from various sources, the majority emanating from personal or professional contacts. Further details of the sources which generated enquiries and later participants is shown in Table 9 below. Recruitment was carried out over a six-month period.

Table 9

Sources Generating Enquiries and Participants

	Professional Contacts (Hospices)	Professional Contacts (Academic)	Charity Newsletter	Twitter	Dementia Nurse	Personal web site	Total
Enquiry Sources	**8**	**5**	**5**	**2**	**1**	**1**	**22**
Participant Sources	**6**	**2**	**0**	**1**	**1**	**0**	**10**

Note. Participant refers to those who have provided qualitative data having completed at least one module of iCare-online.

***Reflexive Comment**: This was a particularly trying time in the research study. Efforts to recruit were disappointing and frustrating and the lack of interest sapped my motivation to devote more time to what felt at times like fruitless recruitment.*

6.4 Qualitative Data Collection

Qualitative data was collected through the online qualitative questionnaire and through iCare-online module reviews that participants were encouraged to provide after the completion of each module as well as ad hoc email communication.

6.4.1 Development of Qualitative Questionnaire

In keeping with the ethos of Phase Two of the study regarding the online delivery of iCare and the encouragement of participant autonomy in relation to access of material, qualitative data were collected remotely using an open-ended qualitative questionnaire. In this study I have used the terms 'questionnaire' and 'survey' interchangeably although others would disagree suggesting that a questionnaire contains scales and requires validation which is more in line with a positivist-empiricist framework (Terry & Braun, 2017). The questionnaire in this study was more in keeping with a qualitative survey allowing for participants to respond freely to questions, at a time and a place of their choosing. Currently, pure qualitative surveys are less frequently seen (Terry & Braun, 2017) and in some instances are not identified as a qualitative method when discussing qualitative research methods (Langdridge & Hagger-Johnson, 2009; Toerien & Wilkinson, 2004), or surveys are seen purely as a quantitative method (e.g. Neale, 2009). Others recognise the advantages and potential of qualitative surveys (Braun & Clarke, 2013; Terry & Braun, 2017) and consider qualitative surveys suitable for exploring a variety of subject areas and capable of generating rich and comprehensive data. Online qualitative surveys/questionnaires remove the need for transcription as participant responses are put into text form and then can be downloaded directly from the survey site ready for analysis. The downside is that unlike an interview there is no opportunity to probe answers further with participants (Frith & Gleeson, 2008) and it is not possible to ascertain how truthful the respondents were in their answers or to what degree they spent time considering the questions (Denscombe, 2008).

Online surveys/questionnaires are "an excellent tool for gathering information on peoples' *views* and *perspectives"* (Terry & Braun, 2017, p. 23) which meant that they could be used to capture data to answer the research question and fitted well with the critical realist framework adopted in this thesis. The questions explored participants' experiences of iCare-online including enquiring about behavioural or emotional changes they had observed (if any) as well as asking about their understanding of self-compassion post iCare-online. Questions were reviewed with my supervisor. Feedback was also received about the feasibility and accessibility of the survey including the

survey questions when iCare-online was piloted. A copy of the qualitative questionnaire can be found at Appendix 14.

6.4.2 Module Review and Email Communication

In addition to data collected through the online qualitative survey further data were collected for analysis via the module review which each participant was prompted to provide by iCare-online. Occasionally participants would email directly with comments or thoughts and as Ryan and Dundon (2008) suggest, albeit in relation to interviews, rapport with participants does not need to end with the end of data collection; unsolicited discourse with some participants continued after the end of the formal research process with impromptu comments. Maintaining an attitude of appreciation for participants' willingness to engage with iCare-online and the necessary research requirements, especially in face of their already demanding caring commitments, perhaps helped to continue the relationship and provide opportunities for further data collection.

6.5 Participant Biographical details

Participants who completed all four modules of iCare had ages ranging from 59-71 (mean age 65) and were White females (5), White and Black Caribbean female (1) and White male (1). Carees were diagnosed with a variety of illnesses:

- Secondary progressive multiple sclerosis (1)
- Dementia/Alzheimer's Disease (4)
- End stage Chronic Obstructive Pulmonary Disease (1)
- Huntington's Disease (1)

The relationship between Carer and Caree was that of partner/spouse (4), and daughter (3). Further biographical information can be found in Chapter Seven.

6.6 Intervention – iCare-online

iCare-online, the intervention used in Phase Two of the study, was based on the face to face version used in Phase One of the study but adapted to more readily fit an online

delivery. It also reflected comments and participants' experience of the face to face version as explored in Chapter Five.

The design of the web-site that eventually hosted iCare-online took note of elements of internet-based behaviour change specified by Ritterband, Thorndike, Cox, Kovatchev, and Gonder-Frederick (2009). This included attractive colours, clean layout and a logical organisation of content all of which contribute to engagement and encouraging use of the web-site (p. 4) combined with a varied delivery of content such as audio, illustrations, graphics, text and video. In terms of adherence to online psychological interventions, the amount of guidance provided by telephone or email appears to play a key part. This may be due to increasing motivation or having a sense of accountability to the facilitator (Beatty & Binnion, 2016). Such guidance does not need to be explicitly therapeutic to be effective but can be of a practical and supportive nature (Andersson & Titov, 2014). This was the type of support and guidance offered to participants, incorporated through personalised email communication in response to individual Module feedbacks completed by participants.

As a result of the findings from Phase One meditations were kept as short as possible as it was clear that participants found the shorter meditations and practices more accessible. Additionally, my (as facilitator) explanatory videos had a focus on warmth, authenticity and compassion as these were facilitator attributes valued by participants in Phase One. Overall explanatory comment was kept as brief as possible, without losing the essence of the Phase One intervention, regarding didactic teaching about mindfulness, self-compassion and caregiver fatigue.

iCare-online mirrored the same four-module format of the face to face version. It was anticipated that participants would take approximately one week to compete a module before moving to the next module. However, the programme did not automatically funnel participants in a sequential order so technically they could have chosen to access modules out of sequence.

The composition of iCare-online had the same four themes as the face to face version but started with a brief Introductory video explaining how the programme would run and asking two questions about participants' hopes for the programme and what were the main challenges they currently faced as a Carer. Module One introduced the concepts of mindfulness and self-compassion; Module Two emphasised the development of a self-compassionate orientation in Carers; Module Three focused on Carer challenges with particular emphasis on carer fatigue; Module Four continued to develop self-compassion practices as they related to the Carer role and introduced a gratitude practice. Table 10 below details the content of iCare-online.

Table 10

Content of iCare-online-Phase Two

	Module 1	Module 2	Module 3	Module 4
Themes	**Introducing Mindfulness & Self-Compassion**	**Blending Mindfulness and Self-compassion into everyday life**	**Compassion in Caring**	**Working with Difficult Emotions Exploring Gratitude**
Content **Written explanation on screen & explanatory video**	What is Mindfulness? 3 Circle Model of Major Emotion Regulation Systems (Gilbert, 2010b) Soothing Touch Components of self-compassion Suggestions for Practice for next 7 days	Affectionate Breathing – explanation; Using the self-compassion break The Pause-explanation Suggestions for Practice for next 7 days	Giving and Receiving Compassion Differentiating empathy, pity & compassion Why you need self-compassion Practising Self-care Caring for the Carer Suggestions for Practice for next 7 days	Introduction to Loving Kindness Loving kindness for difficult emotions Gratitude & appreciation Resources Suggestions for Practice for next 7 days and beyond Final Steps
MP3s of Meditations & Practices	*Body Scan* *Find your soothing touch* *Short Breath meditation* *Short Sound Meditation*	*Affectionate breathing (long)* *Affectionate Breathing (short)* *Self-Compassion Break* *The Pause*	*Giving and Receiving Compassion* *Caring for the Carer*	*Loving Kindness for Difficult Emotions* *Gratitude Meditation*
Online Module Review Questions	Module 1 Review Questions	Module 2 Review Questions	Module 3 Review Questions	Module 4 Review Questions

Total viewing time for participants (excluding meditation/practise time) would be approximately 20-25 minutes per module, although this would vary with the individual.

After each module, participants were directed to a review page with questions to answer about their practice time and their experience of that module. These comments were automatically emailed directly into my inbox. Personalised responses would then be made to the comments participants had submitted and which, it was hoped, would maintain a sense of connection between myself as facilitator and the participant. Sometimes this led to a short email exchange where experiences were further explored, or guidance/encouragement given with any challenges experienced by participants.

6.7 Quantitative Outcome Measures

To facilitate a comparison between Phase One and Phase Two results, the same outcome measures were used, namely the SCS and DASS. (For further details about these measures see Chapter Four, **section 4.6**)

6.8 Qualitative Data Analysis

As in Phase One of the study, reflexive TA (Braun & Clarke, 2006, 2019b) was used to analyse the qualitative data collected in Phase Two via the online/email review exchanges and ad hoc emails together with the open-ended online qualitative questionnaire. Reflexive TA offers flexibility in data collection methods not being limited to interview data. Therefore it is well suited to analysing data generated through online qualitative surveys (Terry & Braun, 2017) and email correspondence (Gibson, 2017).

As in Phase One reflexive TA was used as an analytical method as it was compatible with the theoretical position adopted in this study.

6.8.1 Procedure

A similar data analysis procedure to that outlined in Chapter Four, **section 4.7.2** was followed. The analysis adopted the recursive six-phase model of TA (Braun & Clarke, 2006). By the time of the data analysis the literature review (Chapter Two) had been completed and the Findings from Phase One identified. Thus, the analysis was both inductive, remaining open to the content of the data and deductive influenced by theoretical concepts identified in the literature and the Phase One Findings. Codes

generated through the analysis were, in line with CR, generally semantic, based upon the surface meaning of the data but developed through interpretation, and also latent or researcher-derived using my own conceptual framework to identify implicit and underlying assumptions in the data (see Appendix 8 for examples of coded data).

To avoid duplication, the six-phase model is not repeated in detail, but to be transparent the process of data analysis is outlined:

- The data from the online questionnaires was downloaded and then moved to individual word documents for each participant. This data was combined with the individual module feedback comments.

- The data set was read three times and on the second and third reading initial notes and then codes were inserted into the word document.

- These codes were then moved into Excel spreadsheets and codes clustered to generate initial themes and sub-themes.

- Data extracts were allocated to codes but at this stage it appeared that data had been coded at too superficial a level. The data was then reviewed again and reflected upon, each theme and sub-theme scrutinised and where appropriate themes were changed or merged and codes discarded.

- To gain analytic clarity a tentative written account of the data was started. It was anticipated that a coherent picture would emerge in the writing but this did not occur as it appeared the analysis was stranded in steps 5-8 on Braun and Clarkes' 15-point checklist for a good TA (2006), that is, the data extracts did not sufficiently illustrate the claims being made in the analysis.

- Key texts were revisited (Braun & Clarke, 2006; Braun & Clarke, 2012; Braun, Clarke, & Weate, 2017) to further guide the analysis and the data was reviewed again adopting a recursive process of moving between data extracts, codes and

themes. The use of mind-mapping software helped to visualise the relationship between themes and sub-themes.

- A revised written account of the findings from the analysis was produced (see Chapter Seven).

6.9 Statistical Analysis

Following a similar approach adopted in Phase One the quantitative data obtained from the self-report measures SCS and DASS were not analysed until after the analysis of the qualitative data to avoid influencing that analysis. The Phase Two quantitative data was analysed along the same lines of Phase One. Namely, the data from the DASS and SCS instruments were scored and analysed using SPSS25. Pre-intervention scores were obtained prior to commencement of iCare-online and post scores, approximately 10-14 days after completion of iCare-online. Due to a technical error, data is missing on the pre-SCS scores for three participants as several items were omitted across the subscales; it was considered inappropriate to conduct data imputation to replace the missing data given the small sample size and the extent of the missing data. Hence pre-intervention and post data for the SCS is based on four participant responses (n=4) whereas all participants completed both the pre-intervention and post DASS instrument (n=7).

The results were tested for normality and all measures were normally distributed other than the Self-judgment sub-scale of the SCS for which a Wilcoxon Signed Rank Test was used due to the non-parametric nature of the data. For the other variables a series of paired sample t-tests were used to determine if there were significant pre/post changes in the self-compassion (SCS) and depression, anxiety and stress (DASS) variables. Given that sample sizes (n=4, n=7) were even smaller than in Phase One whilst significance was tested it is very likely that there is insufficient statistical power in the analysis. For similar reasons to those outlined in Chapter Four **section 4.8**, effect sizes were not calculated nor were statistical analyses involving correlations. Percentage changes, pre/ post, in SCS and DASS scores are reported.

6.10 Summary

Within this Chapter the method used in Phase Two for the collection and analysis of qualitative and quantitative data has been described including the recruitment strategy, the process involved in setting up a pilot of iCare-online and the content of iCare-online. The next Chapter presents the findings from the analysis of data from Phase Two.

Chapter Seven: Findings Phase Two

7.1 Introduction

This Chapter presents the findings from the analysis of the qualitative and quantitative data generated from the participants in Phase Two of the study who went through some or all of iCare-online, the intervention the focus of Phase Two. A full discussion of these findings will be found in Chapter Eight. Before the findings are introduced brief participant details are set out together with information about the feasibility, usability and acceptability of iCare-online.

7.2 Biographical Background

Participants in Phase Two comprised nine female and one male Carers, aged from 48-73. Eight out of ten identified as White English, one as Black Caribbean and one as White Northern Irish. The mean age of those participants who completed iCare-online was 65 and the mean length of time the Caree had received their diagnosis (and assumed period of caring) was approximately five years and six months.

Seven participants completed all four modules of iCare-online and the post programme questionnaire and measures. Three other participants part-completed iCare-online but then stopped due to changes in their caring situation and whilst they were unable to comment on the full experience of the programme their responses did contribute to understanding the Carer position and participants' engagement with iCare-online. Table 11 outlines brief biographical details of each participant. Initial pre-iCare-online biographical questionnaires were completed between April–August 2019.

Table 11

Biographical Details of Phase Two Participants

Name of Participant	Age of participant*	Relationship of Caree to participant	Age of Caree*	Diagnosis of Caree	Approximate time since diagnosis*
Fully Completed Responses					
Theresa	64	Mother	86	Dementia	2.5 years
Brenda	60	Mother	91	Vascular dementia	4 months
Zara	63	Partner	57	Secondary progressive MS	14 years
Emma	73	Husband	75	Lewy Bodies Dementia; Parkinson's Disease; Blood cancer	3 years
Yvette	59	Mother	92	Dementia	5 years
Roger	66	Wife	69	Huntington's Disease	8 years
Maureen	71	Husband	77	Chronic Obstructive Pulmonary Disease	6 years
Partly Completed Responses					
Tracey	64	Husband	65	Cortico-basal degeneration	1 year
Diana	48	Mother	74	Motor Neurone Disease	1 month
Kim	Not given	Mother	74	Dementia	4 years

*at date of completion of initial online questionnaire.

In the pre-iCare-online questionnaire four participants described themselves as having a regular practice of meditation as shown in Table 12 below.

Table 12

Phase Two Participants' Prior Meditation Experience as Described in Pre-iCare-online Questionnaire

Name	Regular practice of meditation?	Description
Emma	Yes	Mindfulness of breathing and Metta Barvna [sic]
Kim	Yes	10 years mindfulness meditation
Maureen	Yes	Mindfulness & self-hypnosis but haven't got in right frame of mind lately to do regularly as I used to
Zara	Yes	Mindfulness…various. 6 months

7.3 Feasibility, Usability and Acceptability

The utility of iCare-online can be explored through examining feasibility, usability and acceptability, outcome measures used by Heynsbergh et al. (2018) to assess technology-based interventions for informal cancer carers. Feasibility can be determined by recruitment rates which were not measured in this study. The recruitment strategies adopted (posters, social media, general emails, telephone contact to charities, hospices) prevented the confirmation of a response rate as it was impossible to identify those who had been made aware of the study. Other feasibility measures are frequency of use and attrition rates. All completed participants reported using each module but, in line with the ethos of the programme, to pick and choose what spoke to them, some meditations and practices were preferred over others. The Phase Two attrition rate of 30% was mid-range of interventions examined by Heynsbergh et al. (2018). iCare-online seems to meet this feasibility threshold.

iCare-online was designed to offer a friendly user interface and participants reported on the ease of using it; minor issues with moving between modules were reported by one participant and one non-completer was not able to get the programme to play on older technology. Overall, it appears to meet the criteria for usability. Regarding acceptability, participants did not report any content that they found inappropriate and both quantitative and qualitative findings suggest that participants integrated the concepts into their lives to positive effect. In terms of the above criteria participants found iCare-

online to be a suitable and supportive intervention with the flexibility of an online delivery facilitating ease of access and placing control over participation in the programme in the hands of the participant.

Participants took considerably longer than the originally anticipated four weeks (28 days) to complete all four modules of iCare-online (see Table 13 below). Mean time taken to complete iCare-online and the post self-report measures and qualitative survey (survey completed approximately 10-14 days after completion of iCare-online) was **105** days (15 weeks) with just over 162 days (23 weeks) being the longest time taken to complete iCare-online. This is likely to reflect the busy lives of Carers, and unlike Phase One when participants made appointments with the facilitator for the next session, in the online version of iCare participants had to be self-motivated to start a new module (albeit that participants in both phases had to practise on their own).

Table 13

Completion Times for iCare-online, Self-Report Measures & Qualitative Survey

Participant	**Days taken***
Theresa	162 days
Brenda	120 days
Zara	45 days
Emma	66 days
Yvette	100 days
Roger	142 days
Maureen	99 days

**to complete all four modules of iCare-online, post iCare-online self-report measures & questionnaire*

7.4 Qualitative Analysis

The dataset the subject of the TA comprised individual iCare-online module feedback via forms generated within the programme platform together with an online qualitative questionnaire completed approximately 10-14 days after completing iCare-online. The

Module feedback questions explored such areas as participants' experiences of that module, any behavioural changes they may have noticed following completion of a module, and questions pertinent to the module theme. Details of the online questionnaire questions can be found in Appendix 14.

The analysis of the data generated four main themes and ten sub-themes as shown in Table 14 below.

Table 14

Phase Two Themes and Sub-themes

The Myth of SuperCarer	**Get with the programme!**	**'*Being kinder to myself*'**	**Everyone's a winner**
'*Teetering on the edge*'	What's in the way?	Self-acceptance - '*perfection is not required*'	Seen and now heard
Reality of caring – the would-be SuperCarer in context	Negotiating the content	Permission to practice conscious self-care	More for you AND me
	I've got tools!		
	A deep dive into practices		

7.4.1 Theme: The Myth of SuperCarer

The Oxford English Dictionary defines a 'superhero' as "a person with extraordinary heroic attributes". The superhero according to Steege and Rainbow (2017) evidences a number of common features across the typology e.g. "extraordinary powers or abilities; a strong moral code and belief in self-sacrifice for the benefit of society; a sense of responsibility and guilt that motivates their role; …and a tendency to act alone and apply their individual powers without help from a sidekick" (p. 23).

Whilst Steege and Rainbow (2017) were applying the concept of superheroes to professional caregivers (nurses), as the analysis of this data set continued it became

apparent that woven through it was a construction of the idealised, good Carer as a superhero or rather as a SuperCarer embodying the qualities identified by Steege and Rainbow (2017). Like most superheroes (or heroines) the SuperCarer is an invincible force for good, no frailties allowed and able to solve all problems and brush off the emotional demands of being a Carer, always putting the Caree's needs above their own. Participants seem to be comparing themselves against this constructed fantasy Carer: the SuperCarer is strong, operates alone, easily manages the emotional, psychological and physical costs of caring, is able to banish disturbing thoughts and avoid the pain of impending loss, whilst at the same time is able to negotiate their way successfully through the maze of healthcare and social services professionals, whilst maintaining family relationships and having some form of a personal life.

This theme and sub-themes explore the reality of Carers and the pressure that Carers put themselves under to reach SuperCarer standards and the pain that this inflicts. The SuperCarer wants to be the best Carer imaginable, caring for and protecting their ill loved ones right up until the moment of death. The importance of getting it right, of not letting their loved one down, drives Carers to do the very best they can for the Caree, but often to the detriment of the Carer's own wellbeing. This is particularly so in the case of those caring for individuals with a life-limiting or terminal illness - time is running out to get things right and regrets about care provided could potentially negatively affect Carers for a long time after the death of their loved one.

Aspiring to be a superhero brings an inevitable tension when you are merely human; there is a sense of disappointment, personal inadequacy and failure if you do not quite match up to superhero (SuperCarer) standards. It is the sense of somehow not meeting this ideal, of somehow being 'less than' that seems to have precipitated Carers into joining the research study.

Sub-theme: '*Teetering on the edge*'

Why were Carers interested in participating in iCare-online which they knew would involve some effort on their behalf? What were the underlying motivations to sign up? To varying degrees, it could be said that that the participants who completed iCare-

online were 'teetering on the edge' of not coping. Six of the seven fully completed participants were either receiving counselling or were encouraged to participate by a 'trusted other'. Either they were seen by those close to them as needing some form of additional support or they themselves had recognised that they were struggling to cope with the pressures of being a Carer and had sought professional support, admitting to themselves that the SuperCarer façade was slipping. Theresa, the only participant to self-refer, explained that she "*was teetering on the edge*" (84) of seeking professional support from her GP but to do so would be "*a terrible admission of lacking resilience*" (84), expressing the shame of admitting such a weakness, of not being an invincible SuperCarer. It is useful to differentiate here shame and guilt, as participants specifically refer to guilt in the dataset whereas shame can be inferred from some of their responses. Tangney and Dearing (2002) differentiate guilt from shame as 'I did something bad' (guilt) compared with 'I am a bad person' (shame). Theresa appears to be ashamed to have to admit to her weakness of nearly needing medical support.

The motivations expressed for signing up to iCare-online centred around developing participants' emotional strength and resilience through increased ability to manage stress and challenging emotions (restoring their superpowers perhaps). These are strategic reasons such as wanting to feel "*more resilient again*" (Brenda, 2), to reduce the stress in caring, or as Diana puts it turn off "*the hyper-alert constant sense of worry/concern/stress*" (2). Participants sought to develop greater compassion in caring both for themselves and their Caree or to find greater self-motivation to use the self-care tools they already know about. Some of the expectations for iCare-online were quite ambitious, such as Zara who wanted to develop her:

> *Ability to be more patient…less irritable. .. to have a sense of a future ie my life is not over because nothing can happen outside of my role as carer for my partner. to let go of the anger with family members who don't get it at all… not much!!* (Zara, 1)

Yvette wanted help with her struggle with "*guilt, compassion, self-acceptance*" (3) and for Roger his:

> *main objective for seeking help was to improve my acceptance of the situation and learn ways to cope with the changes in life and the demands placed on me to help with my health / life and so be a better carer* (Roger, 60)

Some were seeking skills to help them cope with life as a Carer which may include new self-compassion skills including finding greater strength and self-belief. For some it was about self-discovery "*to help me understand my erratic emotions"* (Tracey, 4).

Participants were seeking strategies to help them navigate through unknown territory, regain their lost superpowers and to find some new tools for the journey; in essence armouring up.

Sub-theme: Reality of Caring – the would-be SuperCarer in Context

The SuperCarer is generally not called on to perform grand heroic acts but rather an extensive, wearying series of caring duties which for some take up most of the day and night. The SuperCarer would cope with this with boundless energy and enthusiasm and would still create personal time for fun and recreation whilst providing the highest degree of social and personal care despite receiving little or no training in this regard.
The reality of caring is a little different, more complex and nuanced. In the data the participants described the day to day emergencies that they had to handle and for some this got in the way of engaging with iCare-online either at the beginning of the programme or throughout the modules. Theresa, for example, apologises:

> *Unfortunately mum was admitted as an emergency on* [date] *and with work I have honestly not been able to commence, but intend to start in the next few days* (Theresa, 2).

Practical issues abound for Carers on a day to day basis. This may mean liaising with family members who may not understand all that the Carer is doing e.g. "*sorting out my mother's finances and dealing with my sibling!*" (Brenda, 3) or trying to ensure best levels of care through advocating for the Caree and talking to social services or healthcare

providers which can prove frustrating and anger-provoking as Yvette explains of her experience with an continence clinic:

> *It was time consuming and difficult to get mum there. They had sent a sheet to track fluid in and out which was impossible to do. I'd rung to say this was unrealistic because of memory issues. The appointment consisted of lots of fact finding and inputting data in a computer… The whole event upset me for hours later. Why?… It was the complete inability to deviate from what felt like their agenda/script. My questions could have taken 10 mins max. Mum couldn't understand why she was there* (36)

Other practical issues participants faced can mean adapting the house to meet the Caree's requirements and the resultant chaos and disruption that that brings, the physical challenge of lifting a Caree or actually not being able to communicate with a partner and the challenge of this "*no verbal communication with my [partner] and fully understanding his needs*" (Tracey, 5). For some there is the challenge of juggling a job with caring duties or multiple caring responsibilities such as caring for a grandchild, a partner and an elderly parent. Sometimes it can be the sheer tedium of caring which can be challenging:

> *Part of my [partner's] illness is obsessive behaviour and she is fixated on shopping for clothes, yes even more than most women! She feels this is something she can still do as her other hobbies are no longer possible. It absorbs a lot of time and is very boring for me* (Roger, 31)

Time alone can be rare and the constant interruptions to fetch something, pick up a dropped item or just to keep a Caree company can make completing any job or activity the participant had lined up nigh on impossible. Peace is rare, "*The only real peace is when she is asleep such as now, when her carers or another visitor is here or she is out without me which is rare*" (Zara, 27). Physical exhaustion compounded by disturbed sleep is not uncommon which makes coping with life difficult.

Caring is a highly emotive activity and never more so than when caring at the end of life. Participants described waking up feeling stressed and expressing anger that "*I am not able to 'fix' the situation*" (Theresa 42). This is what superheroes do – they swing into action and 'save the day'. Theresa expresses what many participants allude to - the pressure to 'do' something.

Generally, the superhero triumphs over their fears and emotions and the SuperCarer is apparently strong in the face of emotional adversity. It is difficult for participants to admit 'weakness' and feel the pain of being mortal. The dataset revealed the emotional toll that caring can place on you. Theresa talked about waking up stressed, the 'trauma' of placing her mother in a care home and the pain of hearing her mother not always recognising her "*you're not my* [Theresa] *she was kind and caring*" (74). For others it is an ongoing struggle to manage anxiety and stress. Tracey wrestled with the guilt of accepting that she could no longer care for her husband at home "*It's been a really difficult time, adjusting and accepting the changes. I am riddled with emotional guilt but know I could not look after him at home*" (7). Tracey experienced a roller-coaster of emotions which she described as erratic "*ranging from anger to acceptance as well as trying to be kind to myself*" (4). This experience of an array of emotions is mirrored by Theresa who wrote "*I have suffered such emotions these last three weeks*" (74). Participants are capturing a world of strongly felt, painful and difficult emotions which they struggle to process.

As a Carer you are likely to experience many losses and fears. Participants in particular talked about loss of identity, with little space to grieve that loss (and yet if you aim to be a 'good' Carer, which you consider to mean staying strong and impervious to pain, then it can be difficult to acknowledge this loss). Your own identity is subsumed under the weight of caring, as Zara explained "*Ceasing to exist except in relation to* [partner's] *MS*" (37). Emma too recognised how "*it is so easy to loose* [sic] *sight of yourself*" (47) as a Carer. This sense of losing oneself was also expressed by Yvette who echoed the ease with which you can lose 'you', "*As a career* [sic] *you can so easily lose sight that this is your life that you are living as well as supporting others*" (27). Other losses experienced by participants were the loss in connection and reciprocity in relationships "*an*

*emptiness from loss of connection and the laughter we used to have. I guess it was the beginning of recognising we had lost part of the Mum we all knew so wel*l" (Theresa, 66). For others the loss of connection might also include loss of a sex life. Zara poignantly sums up her loss of connection:

> *we are on the same road atm [at the moment] but not the same journey….this is really painful as it separates us and I think makes it virtually impossible for us to know how the other really feels* (29)

For Roger the loss was that of a shared future with his wife "*We had great plans for our future following years of working hard which suddenly were impossible*" (58) or fears for the unknown "*I constantly keep fearing what the future is going to be*" (Emma, 3).

Caring for someone with a life-limiting or terminal illness can be lonely and isolating. Opportunities are lost, for example, paid carers don't turn up at the right time so the Carer is unable to get away to join a family celebration or a social life is severely curtailed as the Caree needs to be put to bed early and there is no-one to stay in the house other than the Carer. These losses and other curtailments to a previous existence are little seen by others and yet are painfully felt.

7.4.2 Theme: Get with the programme!

The Myth of the SuperCarer theme captures the life of participants as they approached iCare-online. Participants carried the pressure of meeting an amorphous unattainable standard as Carer, believing that somehow they needed to find more coping strategies and learn to better hold the pain and grief of caring for someone they loved who had a life-limiting or palliative diagnosis. They were determined and motivated to skill up and 'do' something to help themselves and possibly improve the lot of their Caree. *Get with the programme!* encapsulates how participants then interacted with iCare-online given that framework. Yet, to complete the programme they needed to overcome certain barriers.

Sub-theme: What's in the way?

Whilst iCare-online was considered to be useful to those participants who completed it there were several other participants who did not complete the full four modules and other Carers who expressed interest in participating but never pursued that interest. What gets in the way of Carers using an intervention like iCare-online?

From the post-iCare-online survey data it was clear that participants needed an endorsement from a 'trusted other', a gentle push or encouragement, so as to allow themselves to participate. This 'other' varied from a family member or friend, or a hospice counsellor. Yet behind the 'trusted other' known to participants who enrolled participants in the research was another 'trusted other' who generally happened to be me: I was known to the hospice counsellors and family or friends. From those who part-completed iCare-online the 'trusted other' endorsement came from a hospice healthcare practitioner who was a former colleague of mine or me in my role as lecturer to a student participant. The only unknown participant was a contact made through direct messaging via Twitter. The few others who responded to research advertisements to whom I was an unknown quantity never proceeded past the initial enquiry stage. Trust seems to be a significant element here – Carers need to trust the person suggesting or encouraging an intervention. This is illustrated by Zara's comments *"I have great faith in [hospice counsellor] therefore her endorsement was worth a lot"* (Zara, 67). In the main, the endorsement of iCare-online has come from someone close either personally or professionally to the participant.

The encouragement that Carers seem to need to undertake an intervention that is directed at them personally can perhaps be explained through one of the misgivings identified by Neff and Germer (2017) that self-compassion can be considered selfish; Carers are attuned to putting others first, the "*Habit of putting others need first*" as Yvette describes it (54). As some participants explained, there were times when they themselves got in the way of becoming more self-compassionate, when they struggled with the guilt of offering themselves self-compassion too easily: "*Still found a few occasions when I found self compassion difficult. If I found it easy at times, sometimes*

guilt started to creep in again" (Maureen, 42) or when they judged themselves for not acting in the best interests in the Caree (i.e. for being selfish):

> *When I listened to others saying they wouldn't put their relative in a home or how they cared for their relative or my mother said she didn't want to be in the home I would struggle. I would feel guilty and not very compassionate to myself.* (Brenda, 84)

Time or lack thereof, was also a barrier for many participants. For some, lives were very busy that, despite their best intentions, they simply did not make space to start the iCare-online programme. For other participants the amount of time taken up with unexpected events in family life and the reality of caring got in the way of participation. Kim stopped her participation when life became too full with relationship difficulties, moving house and dealing with the aftermath of her Caree moving into a care home. Yvette had to put her participation in iCare-online on hold when a close family member died but did eventually re-start her participation, whereas Diana was unable to focus and give her attention to the programme when her mother's health quickly deteriorated. Similarly, Maureen was unable to complete feedback on one of the modules as her husband's condition deteriorated and was being admitted into a hospice and her engagement with the programme understandably waned. Roger's participation in iCare-online was prolonged due to alterations to the house required to better facilitate his wife staying at home.

This reflects the life of a Carer - constant demands on time, unanticipated challenges and swift changes in the Caree's health. All fully-completed participants, other than Zara, took well in excess of the originally anticipated completion time of four weeks, again pointing to the complex and full lives that Carers live but also highlighting the challenge of committing to an online programme compared with meeting face to face once a week with a facilitator. For the former there must be a higher degree of self-motivation to keep going without face to face encouragement and motivation. Hence the importance of personalised and timely responses to any participant feedback received.

Reflecting on their journey through iCare-online participants commented on time as a barrier:

> *Ive found each module took me twice as long to complete as the week stated. At the beginning i thought there was a lot of material introduced, it took concentration to take it all in. I wasn't sure i had the time or energy to devote to this* (Yvette, 56)

> *… it was the time factor given all the pressures of my own work and the work I do voluntary, plus all Mum's affairs, which I have kept going throughout. It was a choice thing.. being more compassionate to myself or throwing that aside for the above. Eventually I was able to find a balance as this approach helped me to cope when utilising the programme* (Theresa, 97)

> *Time is the biggest issue, often when you have some time you are too tired / drained to be bothered trying which is why I find the simple exercises most effective* (Roger, 65)

Clearly for some the content of iCare-online was more than they had anticipated and may have been off-putting because of the time commitment. For those that persevered they did not appear to feel pressurised to complete it in unduly quick haste allowing themselves to go at their own pace.

A further barrier that participants had to overcome were difficulties with using the platform iCare-online was hosted on and which frustrated some participants. Yvette didn't like using a computer and got lost navigating around the programme in the early stages and specifically cited the use of technology as getting in the way of her being kinder to herself in the post-iCare-online survey "*An unwillingness to use the computer to access the videos and relaxation exercises*" (Yvette, 54). Others found there were compatibility issues with equipment which may very well have contributed to them giving up on iCare-online:

> *I'm having difficulty opening the programme on my iPad…not sure if the software isn't compatible as it's a bit old! Can open it in my I phone but it's only an apple 6 and the screen is tiny making it difficult to read* (Tracey, 1).

Diana found that the feedback forms on the platform did not work for her and submitted feedback via emailed screenshots all of which would have taken more time than using a system generated form. At the other end of the process Roger and Zara experienced the online questionnaire crashing which again resulted in extra effort for participants.

Sub-theme: Negotiating the content

In line with their motivations for participating, it seems that at least initially participants adopted a strategic approach to iCare-online. This is to say that meditations and practices were used to solve a specific problem or difficulty rather than as a way of developing, for example, say a more compassionate way of speaking to themselves. iCare-online was generally seen as a collection of techniques and tools to aid in surfing the problems and difficulties faced as a Carer in order to avoid drowning under the waves of challenges and problems. Most participants described using practices to calm and soothe, to help with relaxation and to aid sleep "*Used affectionate breathing a few times this made me calm and if practised at nighttime fell to sleep easily*" (Theresa, 68) and "*I try the body scan if I wake up in the night and can't get back to sleep*" (Brenda, 35). Emma described how after Module Two her *"mind was definitely less tense and as this gave me a better night's sleep I was also bodily less tense the next day*" (Emma, 15).

Responses to the practices and meditations varied with some participants commenting in detail about their engagement with the programme content and others making little reference. So, whilst a number of the practices may have been particularly powerful for some participants, they were disliked by another or raised no comment at all. The clearest pattern constructed from the data set was that shorter practices were preferred which perhaps points to the usefulness and ease of use of these practices. Time is precious and anything that consumes a lot of time is likely to prove less attractive to Carers. Hence participants commented on the utility of the short, immediate practices:

Thought they were very helpful, particularly because they were short and had instantaneous results (Theresa, 18)

I find the short simple exercises such as "May I", what do I need right now, taking a short time to "treat" myself and breathing exercises particularly effective (Roger 61)

The short practices most frequently referred to for usefulness and impact were The Pause, Soothing Touch, asking 'What do I need?'/'What's the kindest thing I can do for myself' and the Giving and Receiving Compassion practice. The latter practice is taught initially as a longer practice of circa nine minutes but can be reduced to a simple breath of compassion for self and for the other:

Some of the 'on the job' strategies ie the breath of compassion have helped me to focus on how I am feeling in difficult situations leaving me feeling intact rather than totally mowed down (Zara, 102)

Threaded throughout each module of iCare-online, as in the face to face version, is a gentle encouragement to participants to ask themselves 'what do I need now' or what's the kindest thing I can do for myself right now'. This is part of a turning towards the self, of recognising that in the midst of caring "*I too matter*" (Zara, 106). It is a very portable, practical tool. It acts as a nudge, for example, to rest, take a walk, a drink. It appears a small intervention yet is powerful and can prompt "*allowing myself a bit of me time*" (Roger 47):

The ' what do I need question' is a real gift ...it has led me to have a rest, have a glass of wine, take a short walk or trip to Tesco rather than to keep going becoming more tired and resentful (Zara, 102)

Taking time to feel how it is for you and thinking about how best you can help yourself at that moment in time (Yvette, 60)

This tuning into the self can bring a sense of control to emotions, reducing feelings of overwhelm "*taking the pause and asking what's going on for me right now, brings some control to my feeling helps the situation*" (Theresa, 87).

The Caring for the Carer practice and the explanatory material supporting it within iCare-online has been devised specifically to address the needs of Carers more generally. It is introduced in Module Three as iCare-online moves towards focusing on the Carer experience. Whilst the practice itself may be calming it seems to be a reflective practice bringing participants into touch with the actuality of their caring role. So, for Roger whilst the practice was affecting it was ultimately helpful "*I found the section on caring for the carer helpful as it made me stop and think. I feel very emotional about the situation we are in and it helped me feel better about myself*" (Roger, 34).

The Body Scan is the first meditation that participants meet in Module One. It is a foundational practice in that it introduces an awareness of the body combined with a kindly intention (mindfulness), but it is the longest practice in iCare-online taking around 20 minutes to complete. For several participants it helped with relaxation and sleep yet the time consuming nature of it was a barrier as they struggled to 'find the time' to practice it or the length was off-putting "*I found the 20 minute meditation rather long especially as it was at the beginning*" (Brenda, 86).

Participants were able to identify moments of mindfulness where they tuned in either to their bodies or to their own emotional needs:

> *I tried the shower and found myself extending the time period, which was a positive experience, as usually its a quick in and out! Also more mindful when boiling the kettle and drinking my cup of tea, usually my brain is full of all the things I need to do both personally and work wise; the few moments I have thinking 'whats going on for me right now' makes me more aware of my experiences in the moment* (Theresa, 19)

> *but I try to make the best of it by using the "waiting time" to practice mindfullnes [sic] or just zone out (*Roger, 31)

This is not to say participants found practising mindfulness easy.

> *This is much more difficult at the end of the day (*Zara 14*)*

> *This I found difficult however many times I tried. Lots of problems this week and find it difficult to switch off when trying to remain positive and analyse how I feel* (Maureen 13)

Some participants developed a sense of not being on their own as a Carer, which is significant as a feeling of isolation is common amongst Carers. This reduction in isolation might be through opening up communication with others to reveal a common experience of pain as in Theresa's case: "*Lots of conversations with my brother and sister which revealed we were all suffering in our own way, but were joining forces to cope*" (71). Or it could be a sense of equanimity with the Caree:

> *The use of breath in and out made me think more of mine and mums roles as an equal partnership. That was a huge realisation… I have learnt that my caring role is a partnership, my needs and the thoughts my mum has about her needs both contribute to This relationship* (Yvette, 35-44).

It is Zara who grasps the sense of common humanity as expressed in the programme as seen in this extract:

> *The section on Common Humanity was a massive challenge, I have never before given thought to those suffering in the same way, now it provides comfort, particularly during the night, that maybe others are also up and providing care or being scared about the condition of their partner…*(8)

Participants overall seemed to like the online format. The explanations of key terms were seen as clear and the description of the science underpinning the intervention was welcomed. The variety of content and media format (written, video and audio) was perceived as accessible "*it is like a box of chocolates with the rich mixture of video, chart, pictures etc*" (Zara, 7). However, whilst the programme may have been accessible participants commented that there was still a need to persevere with practices before they became therapeutic:

> "*I have been going over the modules and it does help to give things a go more than once …. I think I needed to spend more time with the programme but have realised that something I initially didn't like was worth looking at again*" (Brenda, 83-91).

It was clear that participants felt free to move through iCare-online at their own pace taking as much time as they needed (rather than the anticipated four weeks) and exercised autonomy in what they chose to focus on and practice:

> *No one hassled me so I could do things in my own time around my caring role* (Maureen, 41)

> *I like the fact that the various techniques allow you to either spend just a few moments or as long as you want / can. Either has had a very positive benefit for me* (Roger, 29)

Despite the positive comments made by participants they were able to indicate when they did not like a practice, or the phrasing used, and did not appear to feel the need to please me by 'liking' all the content of iCare-online:

> *Found mindfulness difficult to use in carer situation although I have used it in past and regularly for other situations but it didn't seem to fit into my caring role* (Maureen, 44)

> *I don't like the use of the word suffering. The recognition that something is really hard is very true but I've needed to give it more of a positive slant* (Yvette, 28)

> *I started this exercise thinking it would sooth* [sic] *current feelings of anxiousness, which was purely related to Mum's situation, however it emphasised negative feelings and despair of failing Mum; the outcome of her assessment was the worst scenario for the family. It was almost like the breath for Mum transferred her feelings of desperation and loss of control in terms of her choice* (Theresa, 66)

In summary, practices can be powerful, supportive and motivating for some and irrelevant or unhelpful for others. Overall participants demonstrated that they had taken on board the encouragement to be autonomous in their use of practices and to choose what works for them and leave what does not. Whilst it could be argued participants felt a need to please me by persevering and completing iCare-online and provide positive responses they were also able to identify and tell me of the practices that they did not like or had 'not worked' for them. A key attribute of the programme appears to be its brief format, certainly no longer or more time consuming that in its current format with its emphasis on the quick in the moment strategies.

Sub-theme: I've got tools!

When participants commenced iCare-online they made frequent mention of seeking tools or techniques to help them in their caring role. This seems to be what participants obtained. Having completed iCare-online participants saw the programme as a resource building intervention encompassing various tools and coping strategies which equipped participants for the serious business of being a Carer. Participants assessed the value of iCare-online through the number of tools they had to draw upon. When asked the question '*What (if anything) did you find useful from any of the modules and if so why?*' each participant who had completed the programme cited one or more practices or meditations as being helpful, with much less emphasis on the emotional aspects (although that was present for some). Tools are perceived as valuable in the business of caring:

> *It's a programme that supports individuals to equip themselves with a varied set of 'tools' that when used frequently allows oneself to practice compassion and self-care on a different level. The effects of which are far reaching in terms of enabling a person to cope with what life throws at them when caring for a loved one* (Theresa, 109)

Tools appear to be used as a way of lifting mood and as a way of helping yourself when you are feeling down. Tools become assets that participants can rely on to help them cope with the difficulty and pain they face – tools form part of a coping strategy. Like a toolkit that can be carried around participants commented on the portability of the iCare-online practices:

> *"I have a suite of exercises to deploy at home, on the move and at work if necessary"* (Theresa, 78)

> *"The meditations are great, like having a friend in my pocket.."*(Zara, 7)

> *"this programme has been an enormous help by practising some simple techniques that really help and can be done anytime, anywhere*" (Roger 46)

> *"So easy to use, at anytime or place, they give time to reflect not react"* (Yvette, 35)

This focus on tools may speak to a sense of isolation and abandonment that Carers feel - they are desperately seeking 'something' to guide them through this confusing maze of changes in relationship with their Caree, symptom management, negotiation with healthcare professionals and social services as well as handle the painful emotions and physical stress that they experience. Perhaps it is not surprising that participants clung to 'tools'.

Sub-theme: A deep dive into practices

Reactions to practices could be very profound and intensely experienced reflecting a deep engagement with a practice, moving beyond a surface, face value meeting with it.

Deep dives into practices could be painful and uncomfortable as intense feelings were revealed and the reality of participants' positions more clearly seen:

> *I have just moved to module 4 and had a massive emotional reaction to 'I am grateful for my life' ….my life is ticking away emptying catheter bags and picking things up off the floor… Hanging the washing out in the sunshine is a bonus …It was a physical reaction .. like a firework going through my body.. not fed up…. scared of what the rest of life will be like…less freedom? even fewer personal choices? having it all mapped out in relation to [partner's]needs?* (Zara, 33-37)

> *I was not prepared for the effect it had. I was very emotional for a number of days and didn't feel like I could continue at that point with the rest of the module* (Theresa 44)

The opening to the depth of unexpressed feelings at times left participants feeling vulnerable and overwhelmed. The turning towards the self and looking inwards as facilitated by some meditations and practices resulted in strong and frequently uncomfortable emotions. For Brenda this turning towards the self happened in the first module and shone a light on how she was feeling:

> *I found myself becoming tearful during Module 1 and at the beginning had thought I was coping with things better. I think I also felt quite lonely* (Brenda, 21)

Emotional experiencing continued and in the last module Brenda became emotional again, something that she seemed uncomfortable with yet at the same time she shows an awareness of why this was uncomfortable for her - the revealing of a painful truth:

> *I tried the first meditation and got very emotional. I had got to "may I be strong" before you! I didn't properly finish the mediation and have avoided going back to it. I don't think I wanted to accept my life as it is* (Brenda, 68)

Despite these reactions she still reported gaining benefit from the programme. Zara had powerful responses to practices which appear to have been insightful:

> *Two practices really put me in touch with my own feelings of loss. I had huge resistance to finding soothing touch instead becoming overwhelmed with sadness at having lost my sexual partner. The second was last weeks response to the realisation of the depth of my loss and my fear about losing my own self* (Zara, 49)

Despite the pain of experiencing hidden emotions or being suddenly floored by facing the reality of the caring situation, participants were sufficiently supported by the programme to hold this new awareness and to introduce kindness to themselves because of the pain they were feeling. Whilst Theresa was wobbled by her reaction to the giving and receiving compassion meditation which derailed her for several days (but which coincided with the distressing decision to move her mother to a care home on a permanent basis) she did then continue with the Module and found consolation in it:

> *Once I was able to 'get myself together' I continued and found great comfort reading about compassion, empathy and pity, which really struck a cord [sic]. In addition, Self-compassion and specifically Caring for the Carer gave me a calmness I haven't had for weeks* (Theresa, 44)

However not every participant experienced strong reactions to the programme content but still talked of benefitting from it – a deep dive is not a prerequisite to gains. For others who did dive deeply and touched pain and hidden emotions participants did surface and generally gained awareness in the process; the experience was not so overwhelming as to prevent participants completing the programme.

7.4.3 Theme: *'Being kinder to myself'*

Self-compassion as defined by Neff (2003b) has three elements: self-kindness (as opposed to self-criticism), mindfulness (as opposed to over-identification) and common humanity (as opposed to isolation). As participants explored the content of iCare-online they engaged with the practices and meditations which opened them to all three aspects

of self-compassion. Participants' prizing of tools suggests an engagement with iCare at a more surface level yet in the sub-theme *A deep dive into practices* it can be seen that for some there is a deeper experiencing which reaches the heart. How did this heart-opening (see sub-theme **Heart Opening** in Phase One, Chapter Five) manifest itself for participants? The essence of heart-opening to the Phase Two participants centres around a sense of being kinder to themselves.

After completing iCare-online participants were asked what self-compassion meant to them; the term for many participants meant 'being kind' to themselves. They variously responded with descriptions of self-kindness such as:

> *It means just taking a few minutes everyday to stop and realise you have to be kind to yourself as well as your loved one* (Emma, 57)

> *It means being kind to yourself, not judging yourself more harshly than you would any one else, giving yourself a break and trying to be your own best friend* (Brenda, 90)

> *Taking a little time to help mself [sic] and recognise that as a carer it is very difficult to cope with all the demands on you* (Roger, 71)

What does 'being kinder to yourself' look like in practice? iCare-online aimed to develop in participants a kinder, less self-critical voice and encourage self-care. In doing so as participants learned more about self-compassion and applied this in their own lives they developed self-acceptance, reclaimed an identity outside that as Carer and discovered the power of conscious self-care.

Sub-theme: Self-acceptance – '*perfection is not required*'

Participants noticed that as they progressed through the programme that they were less hard on themselves whereas before starting iCare-online they could see that they were self-critical at times. As they became more self-compassionate their self-acceptance, of their thoughts, feelings and actions, grew:

I think I'm being kinder to myself in trying not to beat myself up so much when I probably should have paused before reacting … I can still be very critical but feel I can be more objective. I think I feel it is ok to be critical but tend not to dwell on it so much. I find it easier to move on (Brenda, 62-78)

The recognition and validation that caring for my partner who has MS includes much suffering combined with the techniques of Mindfulness and Self Compassion has caused me to talk to myself with understanding and a loving attitude…of course it's hard as opposed to there is something up with me and my capacity to manage (Zara, 101)

Being able to trust in your thoughts to do the right thing without worrying about what others think or their thoughts on care (Maureen, 48)

Developing self-compassion includes becoming kinder in the way you talk to yourself - less of the inner self-critical voice. Participants touched on this in the data set with some evidencing a kinder voice and others wrestling with this as can be seen in Brenda's extract above.

Yet as an initial resistance to this new approach was overcome a kinder voice tentatively began to appear "*I am a person - doing a difficult job- but deserve some compassion*" (Emma, 54) and even blossomed:

My 'lesson' has been about being good enough. How powerful is that?! … I am much kinder on myself. I give myself credit for doing the best I can (Yvette, 45-49)

Self-care was seen by some as the avenue to self-acceptance and through self-acceptance a recognition that they did not have the (super)power to fix every situation and that there was a limit to what they could do. Recognising themselves as experiencing what iCare-online defines as 'caregiver's fatigue' for some participants validated and normalised their experiences. It helped them to see that struggling with fatigue was not

a personal failure, the need to get a grip as Theresa described it, but rather part of the Carer experience:

> *Practising self care, it was the sudden realisation that I wasn't the cause of Mum's suffering and didn't have the power to 'fix the problem'. Identified that I was suffering from carer fatigue and it was a relief to know that it wasn't a weakness* (Theresa, 100)

> *Loving kindness for difficult emotions. This started the feeling of good enough being acceptable to all* (Yvette, 55)

This realisation that there is a limit to what Carers can do, that they cannot solve all their Caree's problems and that they do not have to strive to attain perfection can be liberating for participants.

A further gain from iCare-online for participants is a sense of claiming their life back.

> *Gained 'getting my life back together' to a certain extent …an understanding of meditation and mindfulness which has given me an inner peace I previously found difficult* (Theresa, 92)

> *I think the biggest thing I gained was to realise I was still me and not just a carer* (Emma, 49)

This sense of rediscovering an identity and a life other than as Carer appears to be achieved through several approaches including increased self-care, greater self-acceptance and self-confidence and finding validation as a Carer:

> *I have gained so much ….validation of my experience……the sense I too matter… My self confidence in the role of carer in the face of a world …..the ability to take deep breaths rather than be angry and condemn myself is a very liberating experience* (Zara, 105)

> *The perspective to think more about what i need. To try and reach an understanding of what is good enough. Perfection is not required and never really attained* (Yvette, 53)

The participants refer to finding more "*compassion for myself and less guilt*" (Theresa, 93); as they tune into their own needs and not just their Caree's they became more self-accepting and find what Yvette describes as a sense of 'being good enough'. In essence, the Carers appear to have found a more self-compassionate way of relating to themselves. The SuperCarer ideal is fading.

Participants' conscious and unconscious references to mindfulness and acceptance of their situation and themselves are an important part of recognising the challenges and pain of their situation. This can involve accepting the limits to what you can and cannot do as a Carer which Roger explains:

> *The iCare programme has certainly helped …where I just have to say " THIS IS HOW IT IS" (Roger, 52)*

Each fully-completed participant identified moments of acceptance of feelings and/or their situation. For Carers who have struggled under the burden of the SuperCarer ideal, who have criticised themselves for not being perfect Carers and who have found it hard to accept their negative reactions to the caring situation this sense of accepting themselves is moving:

> *that there is nothing wrong with me in finding some of being a carer for my partner who has a long term degenerative condition challenging sometimes to the very edge of my capacity has not put be [sic] beyond the reach of iCare-online has been almost overwhelming in itself…..*(Zara 43)

> *I have greater acceptance of the situation we are in and coping with the challenges much better …and some of it is just accepting that even a saint would feel like this sometimes* (Roger 28-37)

Sub-theme: Permission to practise conscious self-care

Carers generally, as explored in Chapter Two, are poor at practising self-care. iCare-online emphasised the need for self-care as a way of supporting Carers and reducing caregiver fatigue. This was one of the main foci of Module Three and participants were routinely asked as part of that module feedback to identify their self-care activities. Responses varied but encompassed what might be termed the 'usual' range of activities promoted for self-care such as reading, walking, exercise classes, eating properly, getting enough sleep, listening to music etc.

Within the data set participants referred to a different approach to self-care, a more active acknowledgement that what they were doing was engaging in self-care. For example, Theresa talked about finding what could be termed 'courage' to book a holiday "*The programme gave me the strength to arrange a week's holiday abroad something my husband and I haven't done for three years*" (92) and also to put in place boundaries around visiting her Caree. The value of self-care became clearer and more conscious after completing iCare-online and moves self-care into what Theresa described as being on a 'different level'.

Self-care becomes something to feel less guilty about. Yet there can be ambivalence as in Brenda's case when she states that she feels less guilty about taking time for a relaxing bath but then "*felt a bit guilty when writing down the things I do for myself*" (58). After completing iCare-online Brenda felt that she was "*better appreciating me time and not just going through the motions*" (80) echoing Theresa's experience of developing more conscious self-care. Maureen was aware of several techniques which could support her as she was a therapist, but she was not using them; going through "*the programme made me try different things and choose those that best suited me*" (38). This points to bringing awareness to self-care and a developing intention to practise self-care, whatever self-care may look like to participants. The development of conscious self-care may involve a heightened tuning into the physical self, such as Yvette found:

> *I have always been aware of the need to look after myself and avoid burn out. I regularly have a massage, make time out to see friends, eat healthily. I am now*

> *more likely to listen to my body rather than ignore thoughts and feelings and watch out for stress increasing …. I do get weighed down by my responsibilities but am much more likely to realise that this is happening and take time out for myself* (Yvette 50)

This tuning in is developed through the iCare-online curriculum particularly by asking the 'what do I need right now?' question – it is encouraging participants to pause and turn inward asking 'what do **I** really need' not what others may think is good for me. This move towards an internal self-orientation can be valuable, as in Zara's case, who found it:

> *a real gift … helped me to focus on how I am feeling in difficult situations leaving me feeling intact rather than totally mowed down* (Zara 102)

The impact of small acts of self-care or developing greater awareness of self-care can be profound:

> *By being a little bit selfish sometimes by giving yourself time for yourself, even just a few minutes, can have a massive improvement in the quality of life for both you and the person you are caring for* (Roger, 71)

In order to practise self-care though, Carers must find permission to allow themselves this 'gift'. Superheroes don't normally need to actively look after themselves, they are strong and invincible. Hence the need, as seen in Chapter Two, for this permission to be granted by an external source rather than admitting fallibility. Unfortunately, when this permission is externally bestowed, often by healthcare practitioners or well-meaning friends and family members, it may be implicitly conditional on needing to keep well 'in order to carry on caring' i.e. to meet the societal injunction to look after yourself so as to save the government money (by avoiding the need to bring in formal carers/move Caree into a nursing home, paid by social services). The orientation within iCare (and iCare-online) is different - self-care is encouraged predominantly on the premise that *you*, as an individual, not as a Carer, matter.

As participants moved through iCare-online they began to see that they could allow themselves to practise self-care without needing any external permission:

> *It has also given me the permission to start to get my life back together …this programme has given me the permission I needed to take care of myself* (Theresa, 47-78)

> [Re gains from iCare-online] *The perspective to think more about what I need* (Brenda, 53)

> *It made me find a small amount of time to myself each day without feeling guilty, a time to switch off and be me* (Maureen, 49)

> *I'm being kinder to myself in this way by taking a little time just for me, it may be five minutes to do some breathing, a little longer to do some mindfulness or is possible setting aside some time to do creative, practical things that give me satisfaction and a sense of achievement* (Roger, 28)

7.4.4 Theme: Everyone's a winner

Participants expressed several gains from iCare-online some of which have been explored under other themes (e.g. improvements in mood, heightened awareness of the benefits of self-care, new tools and greater self-acceptance and self-kindness). What participants may not have been consciously aware of was their valuing of being seen by another as an individual in their own right and of their voices heard. Additionally, participants felt that any gains achieved through iCare-online were not solely for themselves. There was a reciprocity with the Caree – they too benefitted through the gains the participants made. Participants described how collectively both Carer and Caree could be positively impacted by iCare-online.

Sub-theme: Seen and now heard

Carers frequently exist in a world where they are *seen* by others, be that family members or healthcare professionals, but as a Carer, rarely as an individual in their own right; their voices are seldom *heard* unless they are lucky enough to receive a therapeutic intervention such as counselling or psychotherapy. This sub-theme attempts to capture the surprise and gratitude that participants felt that someone was genuinely interested in them as an individual, recognised the difficulties of their caring role, wanted to hear how life is and was offering something to help.

The fact that this study was specifically addressing the needs of Carers did not go unnoticed by some participants. That Carers were considered worthy of research was powerful for Zara "*that some one has taken carers as a subject for their research is …amazing*" (47) and that Carers' voices mattered allowed Zara to emerge from the shadows, "*The realisation that someone cared about Carers like me has been great… I feel I can come out as a Carer and not live with the pretence I am just a partner with a little more to do than most*" (Zara, 103). Zara is not alone in mentioning the lack of acknowledgement of Carers and Roger encapsulates this in the following extract:

> *I don't get much praise or recognition as a carer. I do get this from the hospice group and a couple of friends but it feels a bit like Charlie Brown said to Snoopy, "It's like wetting yourself in dark trousers, it gives you a warm feeling but no one notices* (Roger, 38)

It seems as if Carers were particularly grateful that I wanted to hear what they had to say. Participants made frequent references to their gratitude for being involved in iCare-online and the research. Roger expressed his gratitude about both the opportunity to participate in iCare-online and for the support received "*I am so grateful for the chance to participate and Kate's support as I've gone through it. It has made a massive difference to our lives"* (72). This sense of gratitude was echoed by most participants but generally linked to a sense of being 'allowed' to participate e.g. "*Thanks for including me in your project"* (Maureen, 33), Emma added that she was *"really grateful to you [Kate] for allowing me to join your research"* (28). Others also talked about being included in the

research similarly as if it was a privilege being conferred on them *"Thanks for including me in your project"* (Maureen, 33) and "*a huge thanks to you Kate for allowing me to participate in this important research*" (Theresa, 80).

These feelings of gratitude may point to the disenfranchisement by government and society that Carers experience. As seen in Chapter Two, Carers experience isolation and not being truly seen by professionals. iCare-online offered something purely for Carers that was all about the Carer as an individual and an intervention that offered personal, tailored encouragement and assistance. Perhaps it is not surprising, unused as Carers are to bespoke, caring support, that they feel so grateful for an opportunity to be heard and considered worthy of research. Zara in particular comments on the importance of being researched "*I am so grateful Kate has chosen us (unpaid carers) as the subject for her research*" (114) which perhaps explains why she was so angry when she discovered some 12 months after completing iCare-online that I was undertaking further training in mindful self-compassion for healthcare practitioners - that for the first time she had felt there was an undiluted interest in Carers which was now being diverted (in her eyes) to less deserving others. She emailed to say:

> *Your plan to turn your attention to healthcare professionals has filled me with (totally irrational) anger, unpaid Carers have no training, no supervision, no pay, no days off, no paid holiday, no meal breaks, no sick pay, no retirement date, no mileage allowance, no contract of employment, no gloves or protective clothing, no uniform or lanyard of ID….no car park pass for anywhere…….. All we have is ourselves …..Many apologies as I know you are one of the small number of professionals with a concern for us…but my God it's a shit role!… (email correspondence 9.3.20)*

Reflexive Comment*: as I write this I am aware of the discomfort I feel of owning and holding so much power 'over' Carers and yet little did the Carers realise in terms of the research how desperate and grateful I was for their agreeing to participate and thus for giving me the precious data I so desperately sought. I am also conflicted about Zara's angry response - I feel some discomfort for 'letting down' Zara and other Carers by looking*

at others groups of carers who might benefit from self-compassion training and yet a little saddened that professional carers are not considered worthy of attention because they already have so much… are some carers more deserving than others? [written before Covid-19 pandemic].

Participants also seemed to value a personal connection with me despite it being an online programme; that in some sense I was speaking directly to them. Once participants completed each module of iCare-online they were encouraged to provide online feedback about that module. Each participant would then receive from me an email response to that feedback, commenting on any difficulties experienced, clarifying relevant points and offering encouragement. The supportive and personal nature of the email responses that were given to participants were valued – this was not a rote, generic response to feedback. Participants commented specifically on this e.g. "*Kates ready and full responses to each module completed have been helpful and encouraging. You have the feeling of being listened to"* (Yvette, 61). Zara comments on this personal relationship or connection "*I feel held by the structure of iCare-online and the knowledge there is a real person who is going to read this feedback*" (30). The concerns raised by some participants in Phase One that iCare-online could be impersonal seem to have been overcome. Indeed, it is the sense of a real person behind the technology, who was caring and interested in each participant that was recognised and valued.

My presence (through the explanatory videos and meditations) also seemed to add to the sense of personal connection. My voice and manner were perceived as compassionate, calming and comforting by several participants. Yvette commented "*Your voice kind and compassionate is in my head, I can hear you even when not listening to the modules!!!!!" (45).* These sentiments were echoed by Kim *"I really love your manner in the videos, it certainly exudes care and compassion for your participants*" (21). The videos/audios were intentionally framed to be warm and caring in orientation and this seems to have struck a chord with Carers.

Sub-theme: More for you AND me

Participants referred to personal gains and insights they had found from iCare-online and they also were able to identify gains which benefitted their Caree. Every participant referred to improvements in mood post completion of iCare-online. They identified that they were able to give themselves something when they were feeling low, such as taking some time out or using a practice. There is an acceptance of the difficulty of the situation they find themselves in but also for some that there was something they could 'do':

> [Re mood] *Dramatically improved. I am far more positive, accepting and happy, less irritable, more patient and have more energy* (Roger, 62)

> *I think my mood is better. I am much less likely to cry and am less irritable* (Brenda, 81)

> *My mood has improved significantly, I feel less isolated but part of The Community of Suffering , I can offer myself compassion and understanding through some of the meditations…a resource always available I feel l [sic] less hopeless* (Zara, 103)

The qualitative questionnaire specifically asked participants to comment on whether they felt there had been any changes in how they carried out their caring role post iCare-online. Responses to this question or feedback from modules three and four (which particularly focused on the stresses of being a Carer and the caring relationship) referred to the impact undertaking iCare-online had had on the way participants delivered care and/or the caring relationship.

In her feedback after completing Module Four Yvette reflected on her awareness of the reciprocity between herself and her mother and how this impacted on changes to arranging care:

> *I have learnt that my caring role is a partnership, my needs and the thoughts my mum has about her needs both contribute to This relationship. Example. Previously I rush in make mums lunch and all other 'jobs'. This week. I set up what*

is needed so she makes her own lunch, in small stages. In that time I do the other checks in the house. Result she feels she is independent, has been helpful, I do extra things around the house uninterrupted. Everyone is happier in their role (Yvette, 44)

Brenda reported that as a result of iCare-online she "*tried to make the time with my mother of a better quality"* (82). Maureen said that iCare-online helped her to prioritise her own and her partner's needs "*More attention to the needs of my loved one and myself and less about fitting into routines of others*" (40). Roger wrote at length about how through iCare-online and learning to allow himself to care for himself this had resulted in an improvement for the Caree; he was less short-tempered and had greater patience and generally felt "*more positive, in control, content, relaxed, happier and most importantly, a better carer*" (46). In his post iCare-online questionnaire response he used an organisational concept, moving from a vicious to a virtuous circle of care, to reflect the changes he experienced through iCare-online and how this impacted on his caring and he explained this concept as follows:

… because I am in a better frame of mind, more patient and less short tempered, [wife] is also less bad tempered, moody and far more appreciative of what I do for her. My better state of mind has made me happier and that has made her life better and she is happier more of the time. (Roger, 74)

Zara too refers to how taking on board the concepts of iCare-online has impacted her for the better which has in turn improved her caring relationship:

Without a doubt I have been more kind and compassionate towards [partner] …I think I have a different awareness of her suffering Don't be misled I am no saint ……I think the message that by caring for myself I am able to be a more loving carer has made a massive change to both our lives (Zara, 104)

For other participants the impact on the Caree is likely to be through a change in the Carer themselves; if as a Carer you feel better about yourself and the care you provide

then this in turn helps you cope more easily with difficult situations in your caring. Theresa found that Module Four helped her to move from a place of overwhelm with her concerns for her mother to a calmer place;

> *After practicing the module my feelings moved from powerlessness, hurt, feeling desperately sorry for Mum and wishing I could get through to her, to a level of peacefulness, calm and support* (Theresa, 74)

Following iCare-online participants described how they became more compassionate to themselves and their Caree. This may be through putting boundaries in place to protect their 'me' time, improved quality time with the Caree, becoming more loving and kind, developing a greater awareness of the Caree's own suffering or moving to a position of 'we are in this together' rather than 'I *do* care to you'. As has been seen, participants used practices to support them in their caring and through becoming more positive about the care they are delivering they felt this resulted in them coping better with the burden of care.

7.5 Descriptive Statistics

Table 15 presents the results of the scores for the SCS and DASS self-report instruments for Phase Two of the study setting out the comparisons of pre- and post-intervention scores, significance and percentage changes in scores. To aid interpretation of the SCS and DASS scores reference should be made to Chapter Five **section 5.4** for the guidance included there regarding categorisation of self-compassion scores and severity of DASS scores.

Participants reported significant increases in global self-compassion with pre-iCare total SCS scores in the below average category based on Neff's guidelines and moving into the high levels of self-compassion post iCare-online. Significant increases in Self-Kindness and Mindfulness sub-scales are reported together with significant decreases in Isolation and Over-identification. Whilst Self-Judgement reduced and Common Humanity increased post iCare-online these results were not statistically significant.

Depression and Stress scores significantly decreased following completion of iCare-online whilst Anxiety scores noticeably decreased but statistical significance was not reached. The participants' scores for DASS pre-iCare indicated that they fell into the Moderate categories for Depression and Stress and Mild category for Anxiety. After completing iCare-online participants' scores had moved into the Normal category across all three dimensions.

Table 15

Phase Two Pre- and Post-iCare-online Scores Analysed Using Paired Samples t-tests and Wilcoxon Signed-rank Test

Measure	**n= 7**	**Pre-test M (SD)**	**Post M (SD)**	**Mean Difference**	**% change**	**p-value***	**95% CI**
Self-Compassion Scale (SCS) Total	4	2.77 (0.33)	3.92 (0.81)	-1.15	41.52	.005	[-1.62 to -0.67]
Self-Kindness	4	2.60 (0.52)	3.70 (0.20)	-1.10	42.31	.022	[-1.90 to -0.30]
Self-Judgement #	4	3.55 (0.25)	2.40 (0.28)	1.15	-32.39	.125	[-1.20 to -1.00]**
Common Humanity	4	3.56 (0.52)	4.44 (0.43)	-0.88	24.72	.077	[-1.93 to 0.18]
Isolation #	4	4.06 (0.66)	2.19 (0.38)	1.88	-46.06	.022	[0.52 to 3.23]
Mindfulness	4	3.56 (0.66)	4.44 (0.31)	-0.88	24.72	.035	[-0.11 to -3.66]
Over-Identification #	4	3.50 (0.46)	2.50 (0.41)	1.0	-28.57	.011	[0.44 to 1.56]
Depression, Anxiety, Stress Scales (DASS)							
Depression	7	20.29 (11.29)	4.14 (2.61)	16.14	-79.60	.007	[6.28 to 26.01]
Anxiety	7	9.29 (7.97)	1.86 (1.86)	7.43	-79.98	.056	[-0.25 to 15.11]
Stress	7	21.86 (7.69)	7.86 (2.27)	14.00	-64.04	.002	[7.77 to 20.23]

Note: shading represents measures showing significance; # item is reverse scored before calculating a total SCS score, lower scores indicating reduced negative aspects of the SC; M = mean; SD = standard deviation; CI = confidence interval; *= significance level $p \leq 0.05$; **Calculated using Wilcoxon Signed-rank test

7.6 Summary

This Chapter has presented the findings from the reflexive TA of the qualitative data from seven participants who fully completed the Phase Two intervention and three participants who partly completed it. Descriptive statistics generated from the quantitative data were set out. These findings will now be fully explored and discussed in Chapter Eight. Part One of Chapter Eight provides a summary and overview of the findings from both Phase One and Phase Two. Part Two of Chapter Eight provides a critical evaluation and discussion of these findings.

Chapter Eight (Part One):
Summary of Phase One and Phase Two Findings

8.1 Introduction

Part One of this chapter provides a brief overview of the findings from Phases One and Two, highlighting similarities and areas of difference and offers a brief commentary on how iCare-online meets suggestions for good practice. In Part Two of this chapter, the qualitative and quantitative findings are critically evaluated and discussed in light of the existing literature. Whilst the findings from Phase Two address the research question specifically (*What is the impact of a brief online self-compassion programme (iCare-online) on carers of those with a life-limiting or terminal illness?)* the findings from Phase One are useful to reflect upon as they shed light on Carers' experiences of a brief self-compassion programme and illuminate differences between the two forms of delivery and ultimately help in the potential understanding of causal explanations of the changes in mood and functioning that participants reported.

Some of the key elements from the qualitative findings from both phases are drawn together and explored below. Not every sub-theme from the qualitative data across both phases is compared and contrasted due to the constraints of the thesis.

8.2 Qualitative Findings

Figure 1 below is an illustration of the themes generated through the reflexive TA conducted for each phase of the study combined in one thematic map. Links between themes from the two phases are highlighted and the number behind each main theme indicates whether it is a theme from Phase One or Phase Two.

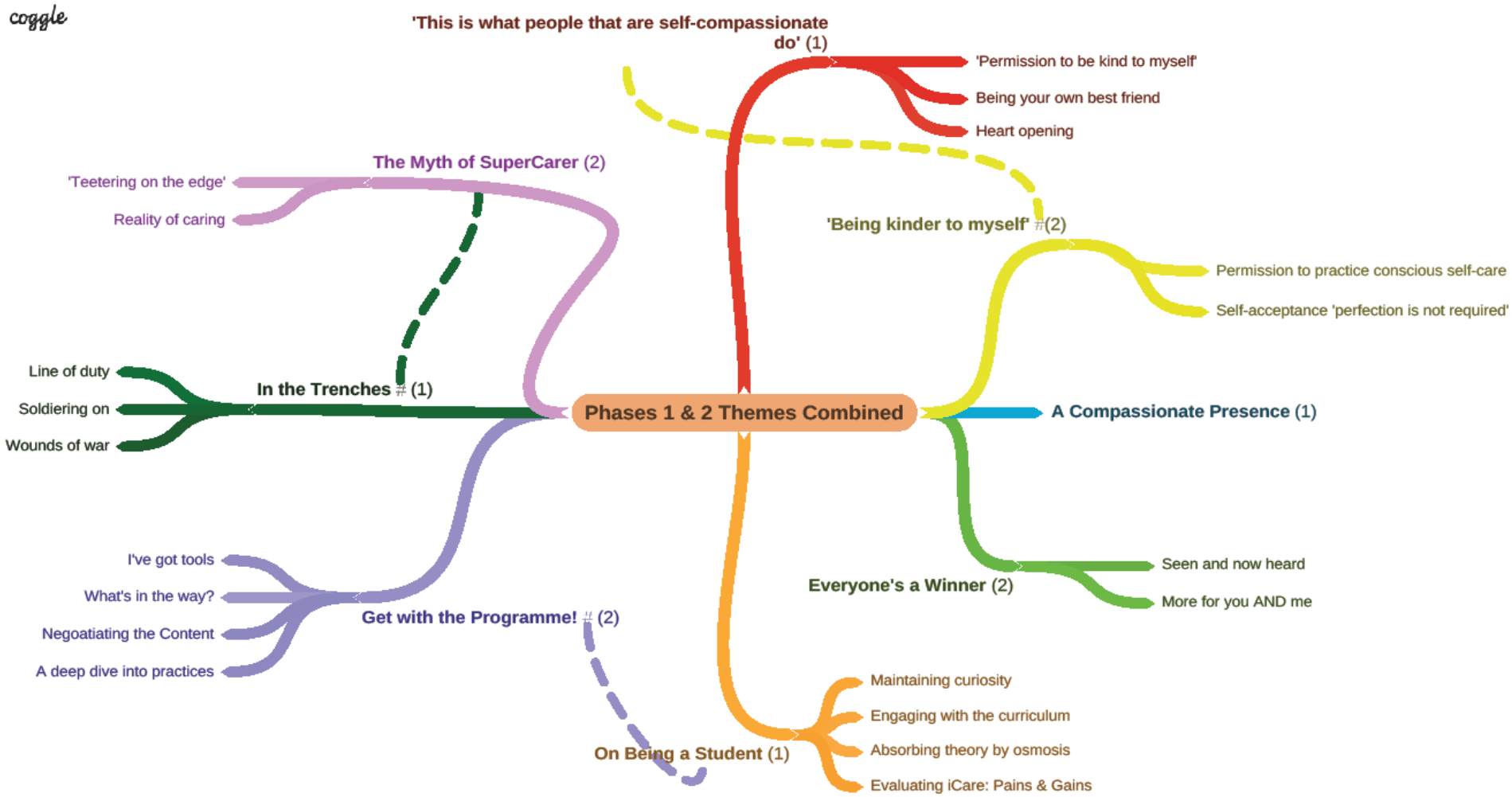


Figure 1 *Thematic Map of Combined Themes from Phases One and Two of the Study*

As previously explained in Chapter Four, I conducted the Phase One reflective TA broadly adopting an inductive approach without reference to literature and theory other than existing theory and experiential knowledge which I had gained as someone trained in delivering mindful self-compassion programmes and who has worked with Carers professionally. Hence the coding and theme development was predominantly directed by the content of the data. The reflexive TA of Phase Two data combined both inductive and deductive approaches as the literature review had in the main been completed by the time of that TA. Whilst reference to the findings from Phase One were not deliberately held in mind during this TA it is likely that the Phase One findings did have some influence as I conducted the TA. This may account in part for some similarities and over-lapping between the findings from both phases, although it is not unexpected that there are similarities as in essence the same programme is being delivered just in a different format. However, I consider there are granular differences between the findings from each phase.

Moving to a finer exploration of the similarities and differences in the qualitative findings, it is apparent that there are connections between most of the main themes within each phase of the study.

The themes of '***This is what people that are self-compassionate do***' (Phase One) and '***Being kinder to myself***' (Phase Two) connect around participants finding clarity over what it means to be kinder to themselves and most importantly give themselves permission to practise self-care. This is captured by the sub-themes '***Permission to be kind to myself***' (Phase One) and **Permission to practise conscious self-care** (Phase Two). As they move through either version of iCare participants start discovering what self-care looks and feels like to them. A difference between the two phases is that in the online version there is a clearer cognizance of self-care, a consciousness of self-care. There is more deliberateness about participants choosing to practise self-care and valuing and prizing the impact of this. This may be due to the longer periods generally taken to move through iCare-online than the face to face version so that participants embed the concept of self-care more deeply. Self-care is certainly emphasised through both versions of iCare and the discovery of a permission to practise self-care and

identification of the value of self-care by participants is one of the most significant elements of both sets of qualitative data.

Two other sub-themes from the main themes above also coalesce. These are **Being your own best friend** (Phase One) and **Self-acceptance – *'perfection is not required'*** (Phase Two). Both these sub-themes point to a kinder, more self-accepting way of treating and speaking to yourself. Subtle differences can be seen between the two though, in that within **Being your own best friend** there is more emphasis on self-critical inner talk and softening the inner critical voice whereas in **Self-acceptance – *'perfection is not required'*** there is a developing realisation of being 'good enough' and recognising participants' own limits to caring, so letting go of the SuperCarer ideals of being the perfect Carer. The emphasis in Phase One on self-talk may arise due to my role as face to face facilitator as I could, and would, gently highlight when participants would use negatively and hurtful language about themselves and suggest more kindly self-talk. For example, asking what would a compassionate caring friend say to you about this? Whilst I would attempt to do this in email feedback on Module comments in Phase Two there was less opportunity to notice and comment on participants' self-talk as I was not physically present with participants. In Phase One over the four sessions participants became more aware of their critical self-talk as there were more reminders and prompts from me about this than there would be in brief, written feedback, which potentially was less easily assimilated by participants compared to in the moment comments delivered face to face.

The two themes **In the Trenches** (Phase One) and **The Myth of SuperCarer** (Phase Two) both point to the painful and harsh reality of being a Carer. In particular, the sub-themes **Wounds of war** and **Soldiering on** (Phase One) and **Reality of caring** (Phase Two) overlap in their sense of highlighting the tedious reality of day to day caring and the pain and losses inherent in the caring role. Subtle differences between the two main themes centre around in Phase One caring conceptualised as war of attrition with Carers carrying out their duty to care for their Caree, whereas in Phase Two Carers appeared to have arrived at iCare-online at a time in their caring when they are particularly overwhelmed and exhausted by their caring hence '***teetering on the edge***' (Phase Two).

The quantitative data may help to illuminate this further; whilst participants in both phases of the study approached the intervention with approximately similar scores for anxiety and stress as measured by DASS, there is a notable difference in levels of depression, with the Phase Two participants scoring over 24% higher on levels of depression than the Phase One participants. This may explain the perception of Phase Two participants being overwrought and desperately seeking 'something' to help them cope in their caring whereas the participants in Phase One, initially at least, appeared to approach iCare more with an attitude of curiosity and a view that there might be something worthwhile to learn to help them in their caring.

A further correlation between themes from the two phases is around how participants approached the iCare intervention. The themes ***On being a student*** and sub-theme **Engaging with the curriculum** (Phase One) and **Get with the programme!** and sub-theme **Negotiating the Content** (Phase Two) address the ways in which participants related to the content of the iCare. Across both phases the shorter practices were preferred as well as the flexible nature of the programme to pick and choose what works for you and to ignore what does not. Similarly, participants from both phases appeared to have a more strategic approach to the programme rather than using it as a mind and heart training for life. This strategic approach is more evident in Phase Two within the sub-theme **I've got tools** where participants were seeking 'something' to help them in their caring and particularly valued the practices as tools to assist in this regard; in this respect iCare-online was seen as resource building. More prominent in Phase Two was the value of tuning into yourself and asking 'what do I need'; this was highlighted as a key part of the intervention. Within Phase One the sub-theme **Absorbing theory by osmosis** refers to the patterns in the data that indicated that key self-compassion theoretical concepts were interwoven in participants' narratives but without participants appearing to be aware of this. It was evident that self-compassion was imbued in the Phase Two participants especially self-kindness but there were fewer references to theoretical concepts.

Interestingly in Phase Two participants were clearer about barriers to accessing an intervention like iCare-online; the need for endorsement from a trusted other is a clear

pattern in the data not seen in Phase One and of course technical difficulties with accessing iCare-online are not experienced in Phase One. Not unsurprisingly participants from both phases identify time as a barrier given the pressured obligations of being a Carer.

The Phase One theme, **A Compassionate Presence,** identified the value of the connection with me as facilitator of iCare to participants whereas in Phase Two I was a remote presence in the online version. Yet despite this remoteness participants still valued a connection they felt they had with me (sub-theme **Seen and now heard**) and valued the importance of, and gratitude for, being recognised and appreciated of and for themselves. In both phases of the study the value of a warm, connected relationship between me and participants was noted in their narratives. It may be that in Phase One due to the face to face nature of the delivery of iCare participants perceived a more intimate relationship with me than in Phase Two and hence this was more clearly apparent in the data. Additionally, participants in Phase One may have felt the pressure to please me given their appreciation, also seen in Phase Two, for the interest and recognition of Carers. Perhaps they did not want to appear ungrateful in the research interview. Despite this possibility, it seems clear that across both phases a warmth in tone and authenticity in communication was important to participants.

Finally, whilst **Evaluating iCare - Pains and Gains** (Phase One) and **More for you AND me** (Phase Two) connect regarding the gains that participants felt they obtained from participating in iCare/iCare-online (e.g. improvements in mood, self-acceptance and coping better) it is only in Phase Two that within this sub-theme the gain for the Caree is developed from the data. Participants were explicit about positive changes in the way they related to their Caree post iCare-online in a way that participants in Phase One did not substantially reflect upon. Again, this may in part be due to the length of immersion in the concepts of iCare-online evidenced by the much longer periods of time participants took to complete the programme (mean time of 15 weeks Phase Two compared to seven weeks Phase One). And as such they had more time to notice how the impact of their own way of relating to themselves radiated out to their Carees.

Whilst the impact on the Caree is touched upon in Phase One it is not to the same degree as in Phase Two.

8.3 Quantitative Findings

The quantitative findings add a further dimension in interpreting the qualitative findings, but it is important to introduce a note of caution here. The sample numbers in both phases of the study are, from a quantitative perspective, very small and even more so for the SCS data in Phase Two where the sample size is only four. Having said that what can be seen is that the Carer participants approached both phases of the study in some distress as evidenced by their DASS scores, see Table 16 below.

Table 16

Phase One and Two Participants' Pre-intervention DASS Scores

DASS (42) Scoring	D	Phase One	Phase Two	A	Phase One	Phase Two	S	Phase One	Phase Two
Normal	0-9			0-7			0-14		
Mild	10-13			8-9	8.89	9.29	15-18		
Moderate	14-20	16.33	20.29	10-14			19-25	23.22	21.86
Severe	21-27			15-19			26-33		
Extremely Severe	28+			20+			34+		

Key: D-Depression; A-Anxiety; S-Stress Scoring guidelines based on Lovibond and Lovibond (1995, p. 9) severity ratings

Following completion of iCare, whether that was face to face or online, all participant scores had moved into the Normal range across all three dimensions of the DASS as shown in Table 17.

Table 17

Phase One and Two Participants' Post-intervention DASS Scores

DASS (42) Scoring	D	Phase One	Phase Two	A	Phase One	Phase Two	S	Phase One	Phase Two
Normal	0-9	8.56	4.14	0-7	4.67	1.86	0-14	12.33	7.86
Mild	10-13			8-9			15-18		
Moderate	14-20			10-14			19-25		
Severe	21-27			15-19			26-33		
Extremely Severe	28+			20+			34+		

Key: D-Depression; A-Anxiety; S-Stress Scoring guidelines based on Lovibond and Lovibond (1995, p. 9) severity ratings

It can be seen from Table 18 below that both phases of the study resulted in participants reporting substantial reductions in negative affect, with the Phase Two results showing an average of a further 57% reduction in depression, anxiety and stress compared to Phase One.

Table 18

Phase One and Phase Two Percentage Change in Post-intervention DASS Scores

DASS	Phase One Post iCare % change	Phase Two Post iCare-online % change
Depression	-47.58	-79.60
Anxiety	-47.47	-79.98
Stress	-46.90	-64.04

The two most comparable brief mindful self-compassion based studies using DASS (Finlay-Jones et al., 2017; Neff, Knox, Long, & Gregory, 2020) appear to have used the 21

item version of DASS which makes direct comparison difficult with the findings from Phases One and Two (which used the 42 item version). Without a guide as to the range of scores for the 21-item version it is not known what category of severity participants in those studies fell into. If percentage decreases in depression, anxiety and stress scores are calculated for those studies then the results from both Phases of this study compare very favourably, in that Finlay-Jones et al. (2017) reported reductions of 50%, 33% and 40% for depression, anxiety and stress respectively and Neff et al. (2020) reductions of 31%, 20% and 32% (study 1) and 13%, 4% and 26% (study 2) for depression, anxiety and stress. It is worth noting that Finlay-Jones et al. (2017) was an online six week intervention with psychology students and the Neff et al. (2020) studies were six-week face to face interventions with health-care professionals.

In terms of developing self-compassion, the results from both phases of the study suggest that iCare, in whichever version, increases self-compassion (see Table 19).

Table 19

Phase One and Phase Two SCS Pre and Post Scores

SCS	Phase One Pre	Phase One Post	Phase One % change	Phase Two Pre	Phase Two Post	Phase Two % change
Self-Compassion (Total)	2.99	3.28	9.70	2.77	3.92	41.52
Self-Kindness	2.47	3.36	36.03	2.60	3.70	42.31
Self-Judgement #	3.04	2.73	-10.20	3.55	2.40	-32.39
Common Humanity	2.72	3.17	16.54	3.56	4.44	24.72
Isolation #	2.86	2.67	-6.64	4.06	2.19	-46.06
Mindfulness	3.03	3.42	12.87	3.56	4.44	24.72
Over-identification#	2.75	2.42	-12.00	3.50	2.50	-28.57

item is reverse scored

In Phase One participants reported a 0.29 point increase in total self-compassion on the SCS whereas in Phase Two participants reported a 1.15 point increase. To contextualise

these increases, Neff and Germer (2013) in their RCT of the eight-week MSC yielded a 1.13 point increase in total self-compassion on the SCS, representing a 43% increase; Campo et al. (2017) in their study of an eight-week mindful self-compassion videoconferencing intervention for young adult cancer survivors reported a 0.74 point increase in self-compassion and a 0.97 point increase in self-kindness and 0.8 point decrease in isolation; Eriksson et al. (2018) in their study of a brief six week mindful self-compassion programme (containing elements of MSC) for psychologists reported a 0.53 point increase in self-compassion and Finlay-Jones et al. (2017) reported a 0.67 increase self-compassion. The recent report of an adapted version of MSC for health-care communities (6 sessions x 1 hr) indicated a 0.47 and 0.62 increase in total self-compassion in two separate studies (Neff et al., 2020).

The increase of 1.15 in total self-compassion in Phase Two is worthy of note given the online nature of the intervention and its brief duration. It is also worth highlighting the substantial increase in self-kindness of 1.1 points and the reduction in isolation of 1.88 points as assessed by the SCS. The increase in self-kindness mirrors the qualitative findings especially the Phase Two theme *'**Being kinder to myself**.'* The sense of isolation as participants started iCare-online, of Carers being on their own and lonely, losing their sense of self is also highlighted in the Phase Two theme ***Reality of Caring – the would-be SuperCarer in Context*** and illustrates the convergence between the qualitative and quantitative data.

Contextualising increases and decreases in the individual components of the SCS is more problematic as few relevant studies report this data focusing instead on the global self-compassion figure. For example, Campo cited above, is one of the few to report on individual SCS sub-scale pre and post scores, and in that study participants were younger and cancer survivors not Carers.

The quantitative results are particularly noteworthy when one considers that participants in iCare (face to face and online) are not students or trainees but individuals operating within a physically and emotionally challenging system where the Caree may be facing impending death or increasing frailty. Thus, changes in Carer well-being could

naturally be expected to decline rather than improve as the Caree's health declines. Although participant numbers are small it is encouraging to see that the quantitative results support the qualitative findings. The improvements in well-being as measured by DASS are not consistent with those of Badr (2014) who found that short-term interventions for Carers do not improve outcomes such as depression (p. 61).

8.4 Commentary on Addressing Good Practice

An exploration of the extent to which iCare-online meets the suggestions for good practice in creation of interventions for Carers now follows. At the time of writing, iCare-online is the only fully self-compassion based online intervention for Carers. Consequently, any comparisons with other studies researching online interventions for Carers are mediated by a number of factors. These include the focus of the intervention being other than self-compassion (e.g. skills based, blended approaches including self-compassion or other well-being interventions), duration (shorter or longer than four modules, increased or decreased time commitment), mode of delivery (e.g. mobile app based, self-guided or with personal support) and target audience (e.g. students, psychology trainees). Despite this it is useful to highlight the following key points contextualised by the most relevant literature.

The Phase Two findings are in line with those of Hopwood et al. (2018). This systematic review of internet-based interventions for Carers of Carees with dementia identified that qualitative findings from included studies were broadly supportive of an internet-based intervention. The most encouraging results in terms of reductions in depression, stress and anxiety were found in online psychologically based interventions (unlike say information provision or decision-making tools) of which iCare-online is one. In designing iCare-online attention was paid to making the programme look attractive and easy to navigate with targeted content aimed at supporting Carers rather than generic content. This was to foster as much trust in the programme as possible, thus meeting suggestions made by Sillence, Briggs, Harris, and Fishwick (2007). The focus on bespoke content was intentional and as Chapter 2 highlighted, this was what Carers wanted (Nissim et al., 2017). iCare in either version satisfies a requirement, identified by Ewing

and Grande (2018), for support for Carers to be "in their own right" (p. 4), that is not as an adjunct to support for the Caree.

The engagement of the facilitator allows for individualising support as recommended by NICE (2019b) on the basis that:

> *if support wasn't relevant or appropriate it would at best be ignored or at worse would result in disengagement with services potentially resulting in both the carer and the person [being cared for] in the last year of life not receiving the care they need* (p. 46)

Whilst iCare-online is a fixed deliverable, the support offered via personal feedback helps to personalise the intervention thus circumventing some of these concerns raised by NICE and meeting calls from Carers for personal support (Hopwood et al., 2018; Köhle et al., 2017). The warm tone woven throughout iCare-online, combined with the personalised feedback, addresses concerns raised about adherence to online psychological interventions that suggest adherence is improved through email support (Beatty & Binnion, 2016). It may be that this tailored support was pivotal to participants overcoming the challenges of day to day caring and lack of time to keep going with iCare online. As Beatty and Binnion (2016) explain:

> *The current finding that increased levels of guidance or support via phone or e-mail that led to increase adherence is consistent with other internet intervention studies targeting both clinical (distressed) samples and non-clinical samples…Possible explanatory mechanisms include guided support might increase motivation to participate… or increase accountability to adhere … Some researchers have posited that the isolated nature of online interventions make it easier for participants to disengage …, and many people report finding self-motivation to engage with online interventions difficult …; therefore, guided support helps to overcome these participation barriers* (p. 791)

This seems to be the experience of Phase Two participants such as Yvette who commented "*Kates ready and full responses to each module completed have been helpful and encouraging. You have the feeling of being listened to"* (61).

The scoping review carried out by Henwood et al. (2017) suggested, inter alia, that carer interventions should aim to build carer resilience which enable carers "to develop strategies to manage the stress and pressure they experience" (p. 91). Whilst that review addressed all carers, not just those caring for those with life-limiting illnesses, resilience building is likely to be no less important for Carers. This study did not specifically address resilience building in Carers yet people with higher levels of self-compassion tend to be more resilient (Martin & Heineberg, 2017; Neff, Hsieh, & Dejitterat, 2005). The development of self-compassion in participants may have played a role in reducing depression, anxiety and stress as well as the offer of tools and self-care strategies that Henwood et al. (2017) suggest are important to Carers thus potentially impacting resilience, although this was not specifically assessed in this study.

8.5 Summary

The results from both Phases of the study suggest that iCare, in whichever version, aids Carers in becoming more self-compassionate, developing a kinder attitude towards themselves, finding permission to practise self-care and in Phase Two practising an intentional, conscious self-care. Additionally, marked improvements in participant well-being across both phases of this study are reported. iCare-online meets suggestions made in the literature for good practice in creating interventions for Carers. In Part Two of this chapter the findings will be further examined relating to the existing literature, a detailed causal mechanism providing an explanation for the findings will be proposed and a critical reflection of the study will be offered including strengths and limitations and areas for further research.

Chapter Eight (Part Two):
Discussion of the Study Findings

8.6 Introduction

The burdens of caring for those with a life-limiting or palliative diagnosis have been explored in Chapter Two and can manifest in several psychological difficulties including high levels of depression, anxiety and stress. Prioritising their own self-care needs is difficult for Carers for a variety of reasons (see Chapter 2, **sections 2.5** and **2.7.3**), and yet meeting these needs may help support Carers' own functioning. Failure to meet the wider needs of Carers may potentially impact on Carer well-being ultimately affecting the Caree's physical and emotional health. The literature suggests this in turn could impact an underfunded health care and social care system in the UK as more support may be needed to support both the Carer and their Caree considering the Carer's poor functioning. To date, targeting increasing self-compassion in Carers as a way of improving psychological functioning, building resilience and developing Carer self-care has not been explored. Addressing Carers' needs through a brief online self-compassion intervention may have wider implications for other time-pressed carers, be they informal carers of those with, for example, chronic health conditions or disability, or professional caregivers such as healthcare practitioners, social workers or teachers.

The aim of this study was to explore the potential impact of a brief online self-compassion intervention for Carers (iCare-online) using qualitative data to explore Carers' experiences, thoughts and feelings of such an intervention. The qualitative data is further elucidated by quantitative data using pre and post measures assessing levels of self-compassion and depression, anxiety and stress.

In summary, this thesis is underpinned by the research question set out in Chapter One **section 1.4** namely, *What is the impact of a brief online self-compassion programme on Carers of those with a life-limiting or terminal illness?* Holding this question in mind this Chapter proffers a discussion of the findings from Phases One and Two of the study, as summarised in Part One of this chapter, contextualised by the relevant literature

outlined in Chapter Two. As this study has been conducted within a critical realist framework it is pertinent to attempt to determine any causal mechanisms (explanations) which may identify the processes which are involved in the development of self-compassion in participants through participation in iCare-online. In addition, it is also important to explore any validity threats to such explanations (Maxwell, 2012, and also see Chapter Three).

Phase One of this study explored a brief self-compassion programme for Carers delivered face to face to establish the acceptability and usability of such a programme before it was then adapted into an online version researched in Phase Two. To provide a coherent and succinct examination of the findings from the study they are discussed in relation to the following key areas:

- An exploration of the main implications of implementing an online self-compassion intervention for Carers

- An examination of plausible causal mechanisms for changes in self-compassion and the impact of these changes on Carers

- In line with CR's axiological stance of social justice, a consideration of the findings in relation to social change including greater recognition of Carers

8.7 Implementing iCare-online

Within the data it was possible to identify several features specific to implementing iCare-online. These are critically examined in relation to the extant literature.

8.7.1 Embedding Self-Compassion takes time for Carers

Carers have busy demanding lives. As was seen in Chapter Seven participants who fully completed all four modules of iCare-online took much longer than the initially anticipated four weeks to complete it. Unlike in Phase One participants did not have to meet with or report to me as facilitator at a given time and so had flexibility to go at their own pace with iCare-online. This resulted in much longer completion times for

iCare-online than the face to face version. The online self-compassion interventions that have been researched (Eriksson et al., 2018; Finlay-Jones et al., 2017; Köhle et al., 2017; Köhle et al., 2015) have time-limited deliveries, not the flexible and open-ended style that iCare-online offered. Consequently, it is difficult to make direct comparisons with those interventions as the iCare-online open-ended form of delivery appears to be the first of its kind to be researched. Whilst direct comparisons with other mindful self-compassion studies is challenging, due to differences in the mode of delivery, content and format of both versions of iCare, the quantitative results of this study followed similar trends reported in the literature. Namely of increases in self-compassion and improvements in well-being as discussed in Chapter Five and Seven (Eriksson et al., 2018; Finlay-Jones et al., 2017; Neff et al., 2020).

The quantitative data highlight an unanticipated difference in outcomes between Phases One and Two which merit further consideration as this difference raises two potential implications that would not have been identified without the input from the quantitative findings. Comparisons between the quantitative data in Phases One and Two indicate that there was a greater increase in global self-compassion in Phase Two compared with Phase One and changes in the SCS sub-scales between Phases One and Two were markedly increased in Phase Two compared with Phase One. This pattern is mirrored with DASS, where the reductions in depression, anxiety and stress were all more pronounced in Phase Two compared with Phase One. This is somewhat surprising as it might have been expected that the face to face interaction with a facilitator, providing the possibility of greater connection than online, would have had more of a measurable impact. This is particularly so given this delivery format partly mimics the standard face to face delivery of MSC when it was first created (Neff & Germer, 2013), although minus the group setting. It may be that a group delivery of a self-compassion intervention is significant. A brief three session group self-compassion intervention for female students resulted in a 21% gain in self-compassion (Smeets et al., 2014) whereas the gain in self-compassion in Phase One was just under 10%.

The qualitative data pointed to the positive value and impact of iCare to participants in both phases. Yet the difference in outcomes between the two phases as measured by the

quantitative outcome measures suggested that there might be a further mechanism involved in developing self-compassion in Carers via an online intervention. Participants of both phases were generally positive about the intervention content, as detailed in the qualitative analyses, and they reported several benefits from participation in iCare. Whilst the modes of delivery were different (face to face compared with online), all participants had an individual experience of the intervention (i.e. no group delivery) and although iCare-online was modified to take account of Phase One participant comments it was not materially different in terms of content. What was different though was the time taken to complete the intervention and it could be that the longer time taken by participants in Phase Two to complete the intervention and the freedom for participants to go at their own pace allowed participants to embed the lived experience of self-compassion and self-care more deeply, which was reflected in the quantitative results.

This is supported by the views of some of the Phase One participants who had questioned the short duration of the face to face version of iCare (four sessions generally delivered over four weeks). Initially these views were thought to be based upon participants' reluctance to let go of the 'compassionate presence' and focused interest in themselves as Carers that they experienced in the face to face delivery format. That is to say, participants were mirroring, in some respects, those counselling clients who find endings difficult with their therapist and who tend to want to hold on to the therapeutic relationship (e.g. Finlay, 2016, p. 139). However, these views may be speaking more directly to the brevity of four weeks and that participants need longer, particularly busy Carers, to fully embrace and embody self-compassion and all that that represents for Carers. Isabel in Phase One was prescient when she commented about the online version:

> *whether the four weeks will be long enough for some people to get into those, that space 'cos for a lot of people it might be too quick and they might then feel cast adrift at the end of it* (249)

This was the reality for the Phase Two participants; without the commitment to meet either virtually or face to face at a set time and place each week participants' best intentions get waylaid by the realities of caring; participants' motivations were such that despite these challenges they maintained their commitment to complete iCare-online, albeit taking much longer than four weeks.

8.7.2 Barriers

The findings from this study are consistent with the literature in that some barriers to participants engaging with iCare-online and self-compassion were identified and these are discussed below.

8.7.2.1 Ambivalence Towards Technology

Recent research indicates that technology can be seen by carers as having a role to play in sustaining them in their caring role (Andersson, Erlingsson, Magnusson, & Hanson, 2017; Leslie et al., 2020). It was anticipated that Carers would have been interested in participating in an online intervention. Yet compared with Phase One, recruitment to Phase Two was more challenging, with Carers expressing interest but then not proceeding to participate in the research. The findings from Phase Two as evidenced by the qualitative data (theme '**teetering on the edge**') suggest that participants justified participation in iCare-online when they felt they were not coping and when they had sought support from a professional. Phase One was easier to recruit to without participants seemingly needing to be struggling. This may point to technology as a barrier and the perceived impersonal nature of the online version of iCare. This is supported by Heynsbergh et al. (2019) who reported Carers' mixed views about technology, expressing doubts about their ability to use technology or who preferred face to face interventions.

Certainly, challenges with the technology did contribute to at least one participant withdrawing from Phase Two; one participant was clear about their dislike with accessing the programme via her computer and there were niggles with the quality of one of the recordings. If the platform upon which iCare-online was based had proven to

be unstable over time and more difficult to negotiate then I consider it highly likely that further participants would have dropped out from the study.

Carer participants seemed more comfortable to sign up for a face-to-face intervention when they did not have to overcome the hurdle of the technology. Yet the average age of participants was not strikingly different between phases with Phase Two participants actually being older on average (58 Phase One to 65 Phase Two), so age per se did not appear to contribute to a fear of technology. No questions were asked about participants' technological literacy in the follow-up questionnaire thus it may be that Carers deselected themselves from participation in Phase Two at the recruitment stage because of their discomfort with technology (Shin et al., 2018). Thus, a technological barrier may be evidenced in the difficulty to recruit to Phase Two. Overcoming any ambivalence towards technology may require a certain degree of desperation to be felt by Carers to precipitate participation in an online intervention, such that they were at a stage in their caring when they would take any help available even if it was online, provided a 'trusted other' (see **section 8.7.2.3** below) could vouch for its value. This proposition is in contrast to findings by Köhle et al. (2018) which concluded that "the intention to use a psychological web-based intervention was not associated with levels of psychological distress" (p. 217) in partners of cancer patients. It could be that it is the nature of the intervention (self-compassion) combined with the mode of delivery (online) and uncertainty about the lack of personal connection with an online intervention that is the barrier. Pywell, Vijaykumar, Dodd, and Coventry (2020) examined the use of mobile-based mental health interventions for older adults (not Carers). Whilst not directly relevant to this study, in terms of both technology and participants, they identified the role users' trust in technology, or a mobile app, played in intervention take-up. Older adults in their study needed a recommendation and endorsement from a medical professional, such as a GP, to overcome anxiety about using technology. This is consistent with the need for a 'trusted other' endorsement of an online intervention Carers appear to require.

8.7.2.2 Time Scarcity

The literature clearly highlights Carers as being time poor (Acton, 2002; Brémault-Phillips et al., 2016; Carduff et al., 2014) and this itself may prove to be an initial barrier to even signing up to an intervention like iCare, despite its brevity, and the online delivery in Phase Two allowing access at home and at a time to suit the participant. Insufficient time seems to be raised as a common barrier too to implementing self-compassion generally (Campion & Glover, 2017; Egan et al., 2019).

In Chapters Five and Seven participants referred to time, or rather lack of it, as a barrier to practising self-care and lack of time clearly impacted on Phase Two participants as they worked their way through iCare-online. The reality of caring involves daily challenges, and unexpected crises, which affected participation and for some prolonged their involvement in the study. This can be contrasted with the findings from Phase One where participants met at an agreed time over four weeks and only rarely changed the meeting dates due to caring commitments. It is much easier to put off accessing an online intervention when you are not accountable to another; without the personalised feedback, something which the participants valued, and which perhaps aided motivation, then the attrition rate may have been much higher. Attrition rates for technology-based interventions have ranged from 14-77% (Heynsbergh et al., 2018). In Phase Two three participants failed to complete the programme (reported reasons centred around issues with their Caree), equating to an attrition rate of 30%. In Phase One there were no withdrawals from the programme.

The lack of free time that Carers experience is also reflected in how participants in Phase Two used the available practices. There was a focus on short, in the moment practices. When one considers the daily life of a Carer, frequently focused on the Caree's needs, juggling medicine, healthcare professionals' visits, appointments, routine care etc then it is not surprising that participants found the shorter practices, even as short as a Pause or a mindful breath, to be valuable. These shorter practices also addressed the participants' initial focus on needing tools and strategies to help them cope with caring.

8.7.2.3 The Need for External Permission

One of the fundamental findings from this study centres around 'permission'. Permission within this study gathers around two axes: permission to participate in a Carers' intervention and permission to practise self-compassion and self-care. The literature points to Carers wanting an intervention that is specifically directed at them i.e. tailored interventions for Carers and not something introduced as an afterthought, or piggy-backed onto supportive interventions for the patient (Nissim et al., 2017). Yet despite the offer of such a tailored intervention, most participants in Phase Two had to be encouraged to participate by being given permission by someone they trusted.

Legitimisation of needs is closely linked to permission to meet needs. In finding a permission to meet your needs there is a recognition of the validity of those needs. Carduff et al. (2014) emphasise the need for Carer needs to be legitimised by professionals and by Carers themselves. Consistent with Carduff et al. (2014) the findings from Phase Two indicated that participants needed a trusted other to endorse their need for additional support to sign up to an online intervention despite it being created specifically to address Carer needs. This trusted other was often a healthcare practitioner and in effect they were legitimising the participants' needs. In addition to a trusted other's endorsement, participants were able to justify or legitimise their own needs when they could see that they were struggling to cope and in Phase Two this is captured by the sub-theme '**teetering on the edge**'. This resembles carer experiences captured by Heynsbergh et al. (2019) who describe carers recognising the validity of their own needs when they were "on the edge" (p. 2206). It is interesting to note that after completing iCare-online, when participants have developed their own internal self-permission, they were able to legitimise their own needs, *"I too matter"*, (Zara, 106) something that was mirrored in Phase One, *'I have needs' (*Olivia, 21), without the desperation of 'teetering on the edge'. Permission is further explored in **section 8.8.2** below.

Carers share some similarities with nurses - Carers are not unlike nurses in the sense that they are seen by society as generally unselfishly always putting Carees [patients] first. Andrews et al. (2020) explored the core process of a *need* for permission for nurses to practise self-compassion and self-care and this helps to illuminate the Carer position.

Unlike the findings in the present study where participants ultimately developed their own permission to practise self-compassion, Andrews et al. (2020) identified permission as needing to come "from another" (p. 6) and from society at large (as in Campion & Glover, 2017). If both the general public and nursing professionals need 'permission' to become more self-compassionate, then it is even more likely that Carers will need this external permission to participate in an intervention that is based on self-compassion. This is especially so given that they struggle with guilt should they fail to prioritise a seriously ill Caree. Echoing the need for permission to practise self-care, family carers in a recent study commented on the need for others, including mental health professionals, to assuage feelings of guilt in carers for putting their own needs first from time to time (Leslie et al., 2020, p. 7).

The societal injunction that the Caree always comes first will need challenging, perhaps repeatedly. Professionals, including healthcare practitioners, will need to be clear and persistent in giving Carers permission to participate in self-care interventions until such time as the Carers themselves (through participation in an intervention like iCare), can develop their own inner permission to become kinder and more self-compassionate to themselves. Through developing this inner permission Carers may then be able to meet some of their own needs. Self-care for Carers may be advocated by Carer organisations (e.g. Marie Curie, 2017) but such exhortations will need to be frequently and firmly repeated. Unless Carers can locate a permission, which *allows* themselves to recognise their own needs, in order to practise some form of self-care, then encouragements to 'look after yourself' will go unheeded.

A lingering doubt remains though. If healthcare professionals themselves struggle to be self-compassionate and are unable to model self-compassion (Andrews et al., 2020) how will they truly see the value of self-compassion and self-care and how authentic will their entreaties to Carers to practise self-care be?

8.7.2.4 Fear of Self-compassion?

Several authors and studies in the field of self-compassion have identified that individuals can fear self-compassion for a variety of reasons (Gilbert & Mascaro, 2017;

Gilbert et al., 2011; Neff & Germer, 2017). Yet contrary to these findings, participants in both phases of the study only briefly referred to any apprehension about becoming more self-compassionate and they did not appear to see this concern about self-compassion as a barrier to gaining something from the intervention. Whilst some participants may have approached the start of iCare/iCare-online with some initial perceptions that self-compassion and mindfulness was a bit 'wishy washy', (Dawn in Phase One comments she did not see herself as the type of person "*that would get anything out of it; this airy-fairy mindfulness stuff*" (138)) substantive concerns about self-compassion were not detected in the data.

Module One of both versions of iCare emphasises some of the physiological responses to self-compassion and uses a model of emotion regulation systems adapted from Gilbert (2010b) to explain some underpinning science. This may have given validity to the concept of self-compassion and thus softened any resistance to the idea of becoming more self-compassionate. What is unknown is how many Carers were deterred by the term 'self-compassion' at the recruitment stage; given the potential for individuals to be uncertain about the term it would be interesting to see if a more positive response to recruitment is achieved through using terms such as 'resilience building' or 'self-care' rather than 'self-compassion' in promotional material.

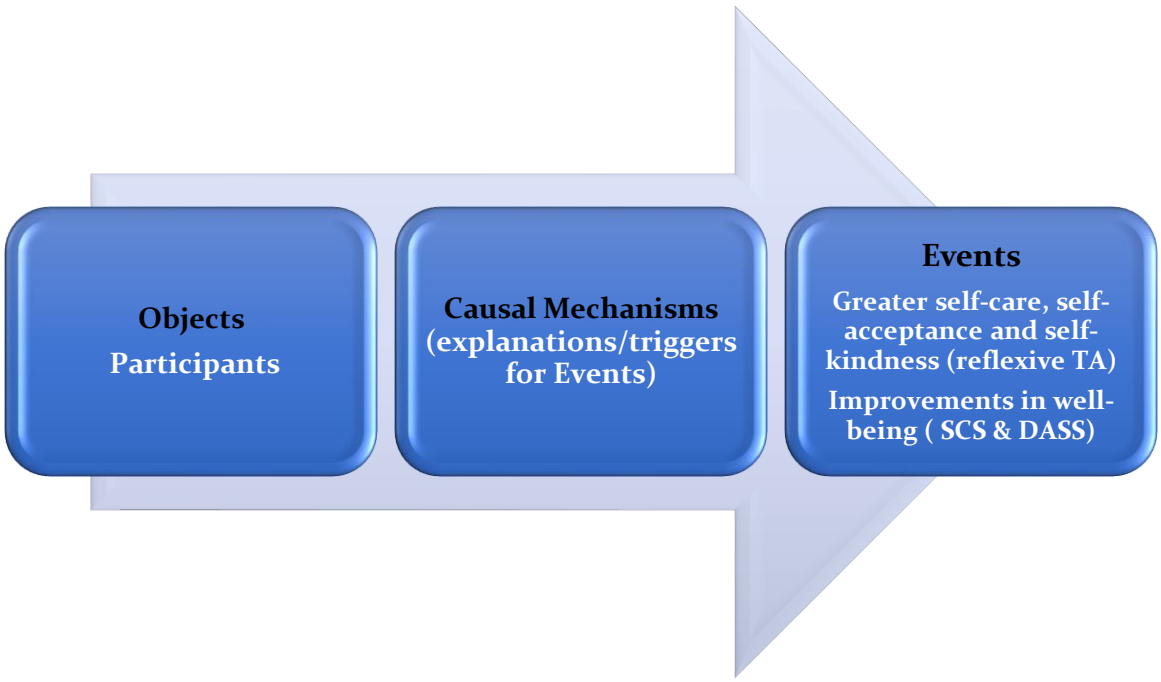
8.8 Exploring Causal Mechanisms: self-compassion, permission and self-care

Identifying causal mechanisms to explain and understand why things happen as they do is a key part of adopting a critical realist theoretical position (See Chapter Three **section 3.4.1**). As such I will now seek to identify a causal explanation for the key findings from Phase Two (as amplified by findings from Phase One). This is one plausible explanation contextualised by these participants with this version of iCare-online facilitated by me at a given time; another researcher with a different interpretative lens and/or different participants and a different facilitator may well identify other causal mechanisms (Wilson & McCormack, 2006). Indeed, further research may offer more convincing causal mechanisms. The aim of critical realist research here is the identification of a key mechanism "with the strongest explanatory power related to the empirical evidence i.e. the causal structure that explains best the events observed" (Bygstad & Munkvold, 2011, p. 7).

Firstly, a recap of the main explanatory terms. In Chapter Three, **section 3.4.1** definitions were offered of three key terms used within CR, and I now offer my interpretation of these terms more closely linked to this study: **Objects** - individuals with characteristics including psychological structures (Easton, 2010). These will be the Carer participants; **Events** – these are external behaviours of the participants which can be identified (using reflexive TA, and the outcome measures SCS and DASS) but these events are always filtered by interpretation and human experience, that is, the interpretation and experience of both the participants and myself as researcher. Descriptions of events will be the findings of this study; **Causal Mechanisms** – these trigger Events and one possible causal mechanism is outlined below. Figure 2 depicts the role of causal mechanisms within the functioning of iCare-online.

Figure 2

Role of Causal Mechanisms within iCare-online



There follows a summary of a causal mechanism involved in the Events that have been described in the findings (Chapters Five, Seven and Eight Part One). At a superficial level it could be considered that a significant causal mechanism is the process of moving

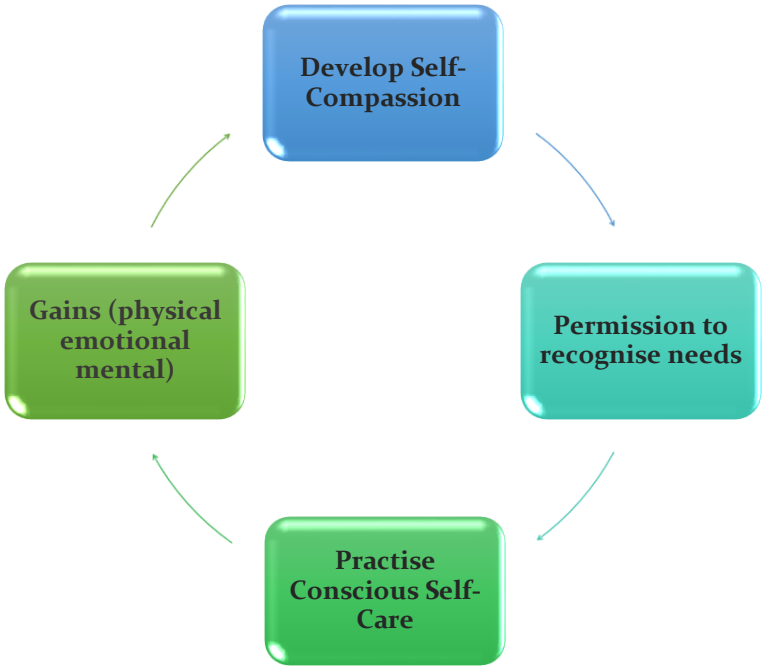
through iCare-online. Through participating in the intervention, the participants who started the programme in somewhat of a distressed state, as evidenced by the qualitative and quantitative findings, achieved a position of greater self-acceptance, practised more self-kindness and self-care which they considered in turn positively impacted on their caring and own well-being. Changes in their behavioural functioning and improvements in their overall well-being, were evidenced by both the qualitative and quantitative data. Yet, what is unknown is why and how this was achieved; the simple process of moving through iCare-online does not provide a sufficiently plausible casual mechanism. I propose that the causal mechanism with the 'strongest explanatory power' is captured by a four-part cyclical Model of Carer Self-Compassion.

Firstly, over the four modules of iCare, participants are gently introduced to the ideas of mindful self-compassion through a variety of ways: guided meditations and practices; explanatory videos; written text and encouragements to try some behavioural changes in day to day life. This is all couched within a warm and supportive delivery and further fostered by caring and individualised email responses to participant module comments. Through practice and implementation of ideas and suggestions participants begin to develop self-compassion. Secondly, as their self-compassion grows participants find a kindlier way of seeing themselves, reducing the pressure on themselves to be perfect and start to hear their own needs, whatever these may be; they discover a permission to recognise these needs. Thirdly, participants begin to practise self-care but with intentionality and awareness. Within both versions of iCare a psychological turning towards the self is encouraged which facilitates more tuning into the self, enquiring 'what do I need right in this moment'? This regular encouragement to turn inwards appears to bring a greater awareness to the value of self-care. Fourthly, participants begin to embody the benefits of the earlier parts; these may be experiencing a greater sense of calm or relaxation, greater self-acceptance and a recognition to the limits of caring (letting go of SuperCarer ideals). This in turn motivates more self-compassion and further adoption of the self-compassion practices and attitudes that are encouraged within iCare and so the cycle continues.

Figure 3 below sets out the four-part cyclical Model of Carer Self-Compassion and a closer examination of each part follows. It is important to highlight that the four parts are not necessarily linear; there is an ebb and flow between each part. For example, this might involve participants needing to remind themselves of all the reasons why it is valuable to meet their own needs (part two) if they are struggling to practise self-care for a time. Or it may be necessary for a Carer to revisit part one if they have been consumed with caring and need to refresh their self-compassion practice and remind themselves of the tools available to them to gain the benefits they have seen in part four.

Figure 3

A Cyclical Model of Carer Self-Compassion



8.8.1 Part One - Develop Carer Self-Compassion

Participants approached iCare-online looking for tools to help them cope with the pressures of caring. What they experience in part one is an understanding of the value of becoming self-compassionate and indeed they do gain some tools that will help them in their caring and which also build self-compassion. They also begin to see with greater clarity the pain of their situation, they *feel* their pain and discover that they can turn to themselves in their struggle and suffering and offer themselves something active to

soothe themselves. Participants were no longer treating themselves as a stranger but emotionally welcoming themselves home. Consequently, they start to move to part two of the Model where they recognise the validity of their needs. But how do participants develop self-compassion?

In Chapter Five I referred to the exhortation by McGehee et al. (2017) to teach mindful self-compassion from a place of being compassionate and offering a *loving connected presence*. McGehee et al. (2017) explain that "Taken together, the three components of self-compassion comprise a state of "loving connected presence" (p. 280). iCare-online was created in such a way as to emphasise warmth, authenticity and connection through both the language used, the vocal tone adopted in meditations/practices and in written communications with participants. In this sense a *loving connected presence* was offered to participants in both versions of iCare but rather unknowingly. It is only in the latter stages of this study that I became aware of the concept; whilst it may have been used at some time in my initial training as a MSC teacher I was not consciously aware of it. So much so that when analysing the data in Phase One I developed the theme **A Compassionate Presence** to reflect the participants' sense of engagement with me, a connection with an interested, warm, soothing presence without recognising the similarity with the phrase '*loving connected presence*'.

In Phase Two the sense of a compassionate presence was reflected more in feelings of being held by the programme and of being listened to, although comments were made about my "*voice kind and compassionate" (Yvette 45)* and the videos exuding "*care and compassion*" for the participants (Kim, 21). I consider this to be fundamental to part one of the Model of Carer Self-Compassion – participants, as best they can, need to experience a sense of compassion and an offering of a loving connected presence before they can begin to offer self-compassion to themselves. What appears to differentiate iCare-online from many online mindfulness and self-compassion interventions (Coster et al., 2020; Finlay-Jones et al., 2017; Fish, Brimson, & Lynch, 2016) is the warm, tailored personalised support provided in response to participant module feedback. Responses to participants were couched to affirm any difficulty, pain or struggle with material and to offer genuine, warm encouragement. This fosters connection with participants, and

I suggest aids motivation to continue with the programme despite time pressures and the challenges of caring.

I view self-compassion interventions such as iCare, as having three elements namely the therapeutic presence of the facilitator/teacher (their Compassionate Presence), the development of a strong enough therapeutic alliance or relationship with participants and the actual therapeutic intervention itself (in this instance the content of iCare). There has been mounting evidence over a number of years that effective therapeutic outcomes in counselling and psychotherapy are due to common factors (e.g. Duncan, Miller, Wampold, & Hubble, 2010; Lambert, 1992; Lambert, 2013) and not purely strategies and procedures determined by schools of therapy/approaches. Whilst the area of common factors continues to be the subject of ongoing debate and research (see Cuijpers, Reijnders, & Huibers, 2019) the therapeutic relationship or alliance with a client (or in terms of this study an intervention participant) is generally named as an important factor. Other common factors include client and extra-therapeutic factors and techniques and interventions. Translating common factors to a therapeutic self-compassion intervention suggest that the therapeutic alliance developed through the medium of a compassionate presence could be considered to be at least as significant as the actual development of self-compassion through taught practices and theory.

The role and influence of the teacher/facilitator in compassion-based interventions does not appear to have been researched and it is only latterly that researchers have brought their attention to the significance of the teacher in mindfulness-based approaches (which, as discussed in Chapter Two, have some overlap with compassion and self-compassion-based approaches). Some attempts have been made to explore the significance of the 'embodied presence' or an 'embodied state of being' of the mindfulness teacher/therapist. Safran and Reading (2008) describe this state as comprising the interaction between client-therapist or participant-teacher involving a "process of mutual influence and regulation at a bodily felt level" (p. 130) with affective communication taking place both consciously and unconsciously. The embodiment of mindfulness teachers of their mindfulness practice is seen as key in enabling group participants to "move towards experiential (rather than conceptual) knowing of

mindfulness" (Crane et al., 2017, p. 995). This is similar to the loving connected presence that mindful self-compassion teachers are encouraged to embody (McGehee et al., 2017) which facilitates a similar experiential knowing of compassion..

In the qualitative study conducted by van Aalderen, Breukers, Reuzel, and Speckens (2014) of, inter alia, participants' views of mindfulness -based teachers, one of the most important outcomes was the emphasis placed by participants on the embodiment of mindfulness by the teacher. This mirrors the findings from this study in participants seeming to value the embodiment of compassion being offered. E. M. Bisseling et al. (2019) in their large RCT of group-based mindfulness therapy for cancer patients identified that it was the therapeutic alliance with the mindfulness-based therapist that predicted reductions in psychological distress not therapist competence. This points to the importance of the presence of the therapist and their ability to build relationships with group members. Interestingly in a further study involving an internet version of the same group therapy (E. Bisseling et al., 2019) results indicated that increases in therapeutic alliance developed at similar rates in either group or internet-based version. Participants in the van Aalderen et al. (2014) study commented on the empowering nature of the intervention and of being required to 'do' something, differentiating it from therapy and seeing the mindfulness intervention as a training. This echoes the present study's findings. Whilst participants valued my compassionate presence, they also valued tools and feeling more equipped in their caring.

The research cited concerns mindfulness-based teachers not self-compassion/compassion-based teachers so the exact significance of each of the three elements of self-compassion interventions I named above has not been identified. Whilst the import of a compassionate presence, used to develop a therapeutic alliance with participants in a self-compassion intervention, cannot be minimised in the development of Carer self-compassion it also seems that the inclusion of a skills-based taught element is both valued by participants and, I consider, essential.

The findings indicate that the loving connected presence embodied by myself as facilitator guides a participant along their own individual path to their own loving

connected presence with themselves, akin to Rogers' unconditional positive self-regard (UPSR) (Rogers, 1959). UPSR can be recognised "as a proxy of psychological well-being" suggest Murphy, Joseph, Demetriou, and Karimi-Mofrad (2020, p. 260) and as a form of self-acceptance. Interestingly Griffiths and Griffiths (2013) found that UPSR was positively correlated with self-compassion. Self-compassion though has a more dynamic component than UPSR in that there is an active intention to soothe, to be with and recognise suffering (yin self-compassion) and where appropriate a protective and active intention to put boundaries in place, to ask for help, to meet your own needs, and even to express anger at the injustice of the caring situation (yang self-compassion) (Neff, 2019b).

The development of Carer self-compassion also requires practice for self-compassion to become a habit; at the minimum it requires a frequent interaction with the core question of both versions of iCare (and of MSC) namely '*What do I need?*'. Whilst this question is central to any MSC training (McGehee et al., 2017; Neff & Germer, 2018) it is particularly important for Carers. Carers are unused to asking themselves what they need in any given moment; their focus is predominantly outwardly facing towards the Caree. This one question can be transformative for Carers and begins to open Carers to experiencing self-compassion. The qualitative findings from both phases point to the power of this question.

Unlike limited self-compassion interventions (e.g. Campion & Glover, 2017), iCare-online develops a sense of acceptability of the concept of self-compassion and self-care which overcomes misgivings Carers may have about these concepts. This is important given, as seen in Chapter Two, that Carers find it very hard to prioritise their own needs and become kinder to themselves in the face of an ill Caree (Dionne-Odom et al., 2017; Nissim et al., 2017).

8.8.2 Part Two – Permission to Recognise Own Needs

Having started to develop self-compassion through engaging with the programme material and absorbed the encouragement in each module to practise self-care, the qualitative findings suggest that participants then gain a permission and commitment

to hear their own needs. This is expressed in the Phase Two sub-theme **Permission to practise conscious self-care.** Participants comment on the programme bestowing 'permission' and this is voiced by Theresa who observes "*It has also given me the permission to start to get my life back together …this programme has given me the permission I needed to take care of myself*" (47-78). The sense of gaining permission is mirrored in the Phase One sub-theme '***permission to be kind to myself***' but in Phase One the participants clearly find their own permission to recognise their needs rather than it being 'granted' by the programme. This could be due to the in the moment interactions with myself as facilitator in Phase One during which I would encourage participants to find their own self-compassionate voice; the online nature of the intervention in Phase Two did not so easily facilitate this 'self-permission'.

Given the limited qualitative research in the self-compassion field, especially as it relates to MSC, the identification of individuals gaining 'permission' to practise self-care has not been reported before in the literature as it relates to the MSC programme, as far as I was able to determine. Further literature searching was undertaken after the identification of the concept of 'permission' given that it is fundamental to the Model of Carer Self-Compassion. Initially I searched articles within my Endnote library authored by Neff. Not one of the 26 articles made mention of 'permission' in any form. A wider search using Chester University's library search facility resulted in three relevant studies: Andrews (2018); Andrews et al. (2020); Pandey, Littlewood, Carter, Randecker, and Davis (2019). Pandey et al. (2019) reported on their findings of a sleep and self-compassion toolkit for grandparent caregivers. No details were provided about the self-compassion element of the toolkit so it is not known how it maps onto MSC but self-compassion was reported as being key "because it allowed caregivers an opportunity to give themselves permission to focus on sleep" (p. A77) which seems to be the first mention of self-compassion as it relates to permission-giving for self-care. Andrews researched self-compassion and self-care for nurses and identified that nurses required permission to practise both concepts. Her 2020 findings have been referenced earlier in this chapter but reviewing her 2018 thesis revealed that she was unable to identify any literature regarding the subject of permission as it related to healthcare or nursing and self-compassion and self-care.

Searches using Google scholar provided a few other results which are worthy of mention as they help to illuminate the link between self-compassion and 'permission'. A six-week loving kindness meditation course for trainee therapists and psychologists found that at the end of the course participants were able to give themselves "permission to be a "good enough student"" (Boellinghaus, Jones, & Hutton, 2013, p. 272). Research indicates that this type of meditation can increase well-being and compassion, but it does not directly map onto MSC interventions, and findings may have been impacted by the fact that participants had all prior-completed an eight-week mindfulness course. Whilst I consider that *self-compassion* has a vital part to play in fostering permission to practise self-care, a review of qualitative papers of healthcare workers' experiences of *mindfulness* training conducted by Morgan, Simpson, and Smith (2015) identified a theme in seven studies dated from 2001-2012 which contained an element of some participants "seeing course as permission or responsibility to engage in self-care" (p. 751).

Yet, in examining each of the seven studies cited, there was only one reference to permission and that related to social workers identifying that they needed permission from the workplace to practise mindfulness; rather it seems that Morgan et al. (2015) inferred a sense of permission to practise self-care in the studies rather than it being specifically identified. Unlike iCare, all these trainings were mindfulness (predominantly MBSR) not self-compassion based and varied in duration between eight to 15 weeks. The only other reference to 'permission' in relation to self-compassion and/or self-care that I was able to identify was the validation of a Mindful Self-Care Scale, conceived for use with treatment of eating disorders but which may well "have utility for those who are care providers, helping professionals, and care takers" (Cook-Cottone & Guyker, 2018, p. 172). This contained a self-compassion item - 'Gave myself permission to feel my feelings' but nothing else related to permission to practise self-care. Hence to my knowledge the clear identification of the significance of finding permission to practise self-care has not been reported before in relation to a self-compassion intervention.

8.8.3 Part Three - Conscious Self-Care

Within this stage of the Model participants more openly practise self-care with intentionality and awareness differentiating it, for those participants that previously practised some form of self-care, from a more a rote approach to self-care. For example, Theresa comments "*made me realise that it is worthwhile consciously taking care of yourself*" (101). It can be seen from Chapters Five and Seven that Carers discovered a nurturing self-care, becoming kinder to themselves; this involves not only behavioural expressions of self-care (e.g. taking time out to walk round the garden, taking a pause) but also internal expressions such as adopting a kindlier inner voice that is more realistic and therefore accepting of less than SuperCarer standards, which Carers are prone to set for themselves (Köhle et al., 2017). This involves an awareness of tuning into their own needs. For example, Roger described self-care as being able "*To say what do I need right now and allowing myself a bit of me time to do it*" (47). The present findings run contrary to those of Dionne-Odom et al. (2017) who found Carers did not engage with self-care practices. Opening to self-compassion can reveal the pain and difficulty of the caring situation and how desperate you may have been feeling. This was true of some participants (see Phase Two theme **A deep dive into practices**). In the face of this awareness, meeting your own needs should not be under-estimated, especially for Carers; it becomes an act of strength and self-compassion to meet your needs when you are suffering rather than to ignore and reject them or meet them in unhealthy ways.

Yet what is self-care, as specifically related to Carers of those with a life-limiting illness, since a definition has not been satisfactorily identified? Northouse et al. (2010) define carer self-care (framed regarding carers of those with cancer but not necessarily life-limiting) as "information, skills, and support needed by caregivers to manage their own physical and emotional health needs, gain confidence in their caregiving role, maintain their social support system, and access resources to ease caregiving burden" (p. 321). This seems to be a common approach to encapsulating self-care often focusing on activities and skilling-up carers but does not capture the conscious aspect of self-care as characterised by participants in this study.

In relation to iCare-online, self-care is more closely aligned with the definition proffered by Lee and Miller (2013) who posit that "personal self-care is defined as a process of purposeful engagement in practices that promote holistic health and well-being of the self" (p. 98). This is consistent with my findings of a 'conscious self-care' practised by Phase Two participants and which reflects the findings of: Godfrey et al. (2011) of self-care involving activities practised deliberately; of Mills, Wand, and Fraser (2018b) that self-care is seen as "a conscious and deliberate practice" (p. 4); and of Dorociak, Rupert, Bryant, and Zahniser (2017) who suggest that "self-care is *purposeful* in that it contains an intentionality component, a planful decision to engage in specific activities or behaviors" (p. 326). Whilst all these studies were directed at patients or professional caregivers their views of self-care seem reasonably apt for Carers. Where there may be divergence though is a focus on *behaviours* and *practices* of self-care. Enhancing self-compassion appears to encourage Carer self-care, but self-care may also be an internal process not visibly seen. Self-care can be manifested through reduced self-judgement and self-criticism and a greater acceptance of the fallibility of being human, not just through taking time out for the self or increasing gym attendance.

All these aspects of self-care were evidenced in the findings of this study. Thus, Carer self-care as captured in the present study, incorporates a kindly, self-caring approach to the challenges faced in being a Carer. This warm-hearted attitude is reflected in the psychological and emotional domain of self-care identified by Lee and Miller (2013) which emphasises "the capacity to maintain a positive and compassionate view of the self and negotiate the demands that arise from the intersection of individual, and environment" (p. 99). Whilst self-kindness is included in their definition it fails to address the need for permission to acknowledge and meet your own needs.

Conscious self-care for Carers, as conceptualised from the present findings, has the following aspects: a conscious or intentional approach to self-care, a kindly self-caring attitude, the recognition of the importance of acknowledging your needs and an inner permission to meet those needs. On the basis that a definition which captures all these aspects is absent from the literature the following definition of conscious self-care for Carers is proffered:

Self-care for carers of those with a life-limiting illness combines the recognition of the validity of personal needs, the development of an inner permission to meet those needs, allied to a kindly self-caring attitude and the conscious practice of self-care

8.8.4 Part Four - Gains for Carer and Caree

The outcome of recognising the value and importance of conscious self-care and of practising it is a positive improvement in mood captured by both the qualitative and quantitative data (Phase Two Theme, **More for you AND me** and see Chapter Eight, Part One). Carers are involved in caring for someone with a deteriorating health condition that will shorten their life, and which may be associated with marked physical, psychological and emotional changes in the Caree. This requires an arduous caring commitment. Consequently, to achieve the gains in mood reported by participants is notable. The data points to the benefits that participants gained from iCare-online but future research may wish to explore whether other participants sabotage their growing self-compassion, either consciously or unconsciously, as resistance is often encountered (Gilbert & Mascaro, 2017; Neff & Germer, 2018), at least in the initial stages of developing self-compassion. As revealed in the qualitative findings, participants also reported on positive impacts on the Caree through participants' greater connection with the Caree and increased patience and understanding of the Caree. It is these gains for both Carer and Caree, it is proposed, that perpetuate the model.

The literature is unclear about a link between self-compassion and compassion for others, that is, if you are more self-compassionate then you will similarly be more compassionate to others. López, Sanderman, Ranchor, and Schroevers (2018) did not find a significant relationship between compassion for others and self-compassion in a large community sample. Similarly, studies of community nurses, student midwives and palliative care nurses and doctors, which considered among other things self-compassion and compassion for others, did not report a direct relationship between the two constructs (Beaumont, Durkin, Hollins Martin, & Carson, 2016; Durkin, Beaumont, Hollins Martin, & Carson, 2016; López et al., 2018; Mills, Wand, & Fraser, 2018a).

However Fulton (2018) identified self-compassion as a mediator of mindfulness and compassion for others in counselling trainees and a weak link between self-compassion and compassion for others was found in college undergraduates (Neff & Pommier, 2013). The picture as it relates to Carers is far from clear.

The evidence of the long hours devoted to caring for a Caree and the protracted care for a Caree to the detriment of a Carer's own health indicates that Carers are not lacking in compassion for others. Hence it is very likely that the participants were highly compassionate and caring of their Carees before they started iCare-online despite scoring relatively lowly on the SCS and yet they reported on positive changes in their caring after completing the programme. A link between self-compassion and compassion for others was not explored in the present study and remains an area for further investigation, a point highlighted by Quaglia, Soisson, and Simmer-Brown (2020).

8.8.5 Stepping Away from the Cyclical Model of Carer Self-Compassion

What happens if a Carer steps away from the Model? Stepping away may be due to changes in the Caree's health requiring more care including a move into the terminal phase, new additional caring responsibilities arising with other members of the family needing support or changes in the Carer's own health. Self-compassion 'practice' (either intentional meditations/ guided practices or informal in the moment practices) which supports the Model may stop; there may be a forgetting of the value of meeting your own needs when faced with a crisis. The present data does not provide an answer to this question. A longitudinal study may provide more information to support a new causal explanation.

My hypothesis is that the development of self-compassion cannot fully mitigate the effects of a Caree becoming more poorly and moving into the active dying stage. However, the longer a Carer stays within the Model the greater the likelihood that all parts of the Model become more deeply ingrained, so that resources are available to draw upon in a crisis. A recent introduction to the Model is unlikely to provide much of a buffer to the reality of imminently losing someone you love. Yet Carer Self-

Compassion if embedded through more sustained involvement with the Model may offer resources at times of pain and suffering to buffer against the most negative impacts of grief and could positively impact bereavement, but this requires further research to explore more deeply.

8.8.6 Validity threats

CR looks for alternative possible theories or conclusions drawn from the data as a way of identifying 'validity threats' (Maxwell, 2013) to any identification of a causal mechanism, (see also Chapter 3, **section 3.8**). Above I identified a potential causal mechanism that may explain the Events represented by changes in self-compassion, well-being and self-care following participation in iCare-online. Possible validity threats to this causal mechanism could be:

- that Events occurred as a result of a normalisation of participants' caring experiences and reactions as they moved through the programme.

- the pre-iCare-online SCS scores showed high levels of isolation suggesting that participants were particularly isolated and in the qualitative data the participants' narrative refers to being unseen and unappreciated. At completion of iCare-online the sense of isolation appears to have reduced as reflected in the SCS sub-scale score for isolation, potentially due to email feedback at the end of each module and a greater sense of connection which may account for improvements in well-being.

- Some participants were also receiving counselling at the time of the intervention and it is unclear what impact that had on levels of self-compassion, self-care and well-being.

- Participants clearly expressed their gratitude for my interest in the Carer experience. The positive comments and improved self-report measures may reflect socially desirable responding (Elliot, 2015; Paulhus, 2002) on the part of

participants as they may have wanted to reward me as researcher for that interest and recognition of them as Carers.

- ❖ Prior meditation experience in the participants may have positively impacted the findings.

Despite these validity threats I still consider the causal mechanism identified in **section 8.8** to be the most convincing mechanism for the following reasons:

- Within the Model of Carer Self-Compassion the identification of the key elements of *permission* to recognise needs and the practice of *conscious* self-care for Carers are novel concepts. These better explain Events than normalisation of Carers experiences or reductions in isolation. Neither of these offer the motivating and active components of self-compassion that *permission* to recognise needs and practising *conscious* self-care do. It is these two elements which appear to lead to actual changes in self-talk and behavioural and/or emotional responses.

- It is highly unlikely that within therapy participants are given self-compassion practices, skills and tools tailored for the Carer experience and which participants can use in the day to day reality of their caring; in fact for those receiving counselling it was their counsellor who suggested participation in the study, indicating that there was a recognition that something other than therapy could be useful to participants. An online compassion-focused intervention was found to be effective regardless of whether participants were receiving concomitant psychotherapy or not (Krieger et al., 2019, p. 443) pointing to the possibility that iCare-online and psychotherapy or counselling may be addressing different participant needs.

- Whilst participants may have been grateful for my interest, they were still very willing to share what they did not like about iCare-online (e.g. too lengthy

meditations; language that failed to resonate, clunky navigation of the site or practices that were not helpful). Their continued participation was evidence of the value they were obtaining; Carers are too busy and pressured to persevere with something that requires effort and commitment if there is no perceived benefit. Their desire to please and to 'care' for me as researcher is not sufficiently strong that it would overcome any frustration and disinclination to continue – the three participants who failed to complete iCare-online giving as reasons changes in caring commitments, had no compunction in leaving the study.

- Only three participants out of a total of seven participants who completed Phase Two had prior meditation experience. It is unclear what impact this prior experience had on their participation in iCare-online. However, iCare-online is not a predominantly meditation-based programme - Carers in the midst of caring cannot disappear to practise 20 minutes of a sitting meditation. There is much more emphasis on 'on the job' practices that provide the tools that participants wanted unlike standard meditation-based interventions. It is this, rather than meditative experience, together with a clear focus on the value of kindly self-care that is more likely to have generated the quantitative and qualitative findings.

Other validity threats (researcher bias and reactivity) were discussed in Chapter Three **sections 3.8** and **3.9.**

8.9 Social Justice Implications

CR has an emancipatory goal of enhancing human freedom and flourishing (Archer, 2017) which aligns with my axiological position of promoting social justice. The aims of the study did not include challenging social injustice as experienced by Carers, yet in adopting a critical realist theoretical position it is incumbent on me to at least identify areas for social change, including greater recognition of Carers.

8.9.1 Carer Capital

At the commencement of this study my awareness of some of the injustices inherent in the Carer role was rather limited. Within the findings from Phases One and Two the

pressures inherent in caring became much clearer, see Phase One theme **In the Trenches** and Phase Two theme **Reality of caring – the would-be SuperCarer in context**. Participants expressed the psychological, physical and emotional pain they were experiencing as part of being a Carer. Yet as I conducted the literature review it became apparent that whilst this pain was recognised, the literature exploring Carer experience and well-being would frequently refer to the impact of Carer functioning as it related to health care costs. It was argued that Carers required support so as to minimise costs that might be incurred, either through direct medical or psychological support to the Carer: if their own mental or physical health declined as a result of their caring responsibilities; or, if their ability to care for the Caree was impacted. Either consequence would have a subsequent negative effect on healthcare and welfare services. This was discussed in Chapter Two **section 2.7.3** (e.g. Dionne-Odom et al., 2017; Hampton & Newcomb, 2018). Support for Carers is justified on the grounds that the functionalisation of Carers can be seen as providing an expedient plaster for debilitated healthcare and welfare states; support for Carers as individuals in and of themselves does not appear to be recognised. Hence the call from participants, "*I too matter*" (Zara 106) or "*I have needs*" (Olivia, 21).

A not insubstantial portion of the caregiving literature sustains a narrative of Carers supporting an ailing healthcare system and with that an expectation that Carers will continue to provide the degree and extent of care that they already do. With an ever-ageing population both here in the UK and worldwide (United Nations, 2020) this burden of care will only increase. As Leslie et al. (2020) comment "governments have come to rely heavily on family carers… to care for older adults and reduce the demands made of formal health and social care systems" (p. 1). Yet despite this heavy burden it appears that the cultural capital (Bourdieu & Nice, 2010) of Carers or indeed other unpaid carers or caregivers, (what could be termed Carer Capital), carries little significance societally. Long-term suffering and the daily minutiae of unpaid caring is not glamourous, 'sexy' or visible.

At the time of writing the social and media commentaries about the current Covid-19 pandemic revere professional healthcare caregivers including those within the

previously under-valued social care system; all now proudly promoted as bastions of self-sacrifice and compassionate care, forming a collective of medical heroes and celebrated weekly during the lockdown (Clap for Our Carers, 2020). There is no denying the immense contribution these professional caregivers have made to the UK's healthcare system, offering dedicated care in gruelling circumstances sometimes sacrificing their own health and, very sadly, occasionally their life. Yet, there is little or no mention of Carers, trapped at home with a shielded Caree providing 24 hours per day care, unpaid and unrecognised, generally willingly undertaking as Zara described "a shit job". The King's Fund reported that as a result of the pandemic, carers, which includes those caring for a Caree, will all have seen an escalation in their caring responsibilities due to an increased unmet need for social care, as social services were put under pressure (Bottery, 2020). For example, onerous expectations were placed upon Carers such as recommendations for Carers to undertake administration of end of life drugs to their own Caree, including setting up cannulas, (Hill, 2020) or being asked to learn a medical intervention normally carried out by nurses (Zara, personal communication 25th June 2020).

The omission of Carers from the world-wide medical heroes narrative (Bauchner, Easley, editorial, JAMA, & Network, 2020) merely reflects the everyday life of the Carer - unpaid and unseen. This is Carer Capital. Yet, whilst they struggle under the pressures of caring, participants in both phases of the study carry on caring, feeling invisible and losing a sense of themselves as individuals but in the main not questioning their invisibility to the wider public.

There are Carers who clamour and shout for change (Zara in this study in particular is vociferous about the injustices inherent in being a Carer) but overall the participants in both Phases were too tired and wrung out with caring to find the energy, it seems, to challenge the status quo. It is not the intention that a self-compassion intervention should arouse a passionate campaigning response in participants to the inequities inherent in the caring system. Yet a future iteration of iCare (face to face or online) could include more emphasis on elements which reflect the protective aspect of yang self-compassion (Neff, 2019b). This could have the potential to empower Carers to speak

their truth with clarity, but without aggression, in recognising the boundaries to the care they can provide and to challenge the expectation from healthcare professionals in particular that they will assume more caring responsibilities than they feel able to. Campaigning for increased recognition and valuing of the role that they undertake will come down to, inter alia, a few crusading Carers who do have energy to challenge the prevailing narrative, carer organisations and researchers who highlight the Carer reality.

8.10 Limitations of the Study and Future Research Opportunities

8.10.1 Limitations

Each phase of this study used an opportunity sample of people who identified themselves as a Carer. Not only may these samples not be representative of all Carers but by recruiting 'carers' of those with a life-limiting diagnosis I was automatically excluding those people who did not identify as a carer. As Carers struggle to self-identify as carers (Carduff et al., 2014) my referring to 'carers' throughout all recruitment material seems flawed. Having spent most of my professional counselling background in a hospice setting, the term 'carers' is in common parlance and it was only undertaking the literature review that I realised that I may have inadvertently excluded potential participants by not 'speaking' to them in recruitment material.

Recruitment to Phase Two proved to be challenging. As a result the number of participants recruited, seven Carers who completed iCare-online, fell short of the original target of 10-20 participants, which is a suggested sample size for a medium sized TA project which each phase of the study could be said to represent (Braun & Clarke, 2019a). In hindsight, better use could be made of social media, for example, following some of the suggestions highlighted in Hansen, Sheehan, and Stephenson (2017) such as targeting illness blogs or using a video message on Facebook to aid connection with potential participants rather than rely on email. As Braun and Clarke comment though "Bigger isn't necessarily better. The bigger the sample, the greater the risk of failing to do justice to the complexity and nuance contained within the data" (Braun & Clarke, 2016). The sample size was sufficiently large enough to generate data that met the objectives of the present study (Shaw, Bishop, Horwood, Chilcot, & Arden, 2019) and I consider that through a rigorous TA I have done justice to the complexity of the data.

Not only was data generated through the qualitative questionnaire, the four-module feedback provided additional data for use in the TA thus extending the data pool. A pragmatic decision was taken to stop recruitment after five months in order to complete the thesis within a reasonable time frame. Yet the poor response to recruitment was also data in and of itself, which I have reflected upon in the previous paragraph and in **section 8.7.2**.

The overwhelming majority of participants were White British in ethnicity, middle-aged and female. The lack of diversity may be related to my recruitment procedures which included contacting hospices, which are generally not culturally representative (Calanzani, Koffman, & Higginson, 2013; Campbell, 2019), or recruitment was not sufficiently targeted to reach hidden Carers (Social Care Institute for Excellence, 2019), discussed in Chapter Two, **section 2.3**. Male Carers were underrepresented in the study despite accounting for a significant minority of Carers. As men tend to have slightly higher levels of self-compassion than women (Yarnell, Neff, Davidson, & Mullarkey, 2019) it may be that an intervention that builds self-compassion did not appeal to male Carers. Teachers of MSC anecdotally report that participation rates by men in the MSC 8-week programme are around 15-20% (Center for Mindful Self-Compassion, 2019) so that having one male participant in the Phase Two study mirrors this percentage. The term 'self-compassion' may also not resonate with men and is an area worthy of further exploration.

From a quantitative perspective the rather limited descriptive statistics would curtail any claims to generisability. Yet this view is based on statistical-probabilistic generalisability (Smith, 2018) which informs quantitative research. This is a predominantly qualitative study within which I have provided a rich, granular exploration and interpretation of participant experience. As such this study attempts to provide descriptions which meet the suggestions of Smith (2018) and Tracy (2010) for generalisation based on transferability. I have aimed to achieve this through reporting findings "that invite transferability by gathering direct testimony, providing rich description and writing accessibly and invitationally" (Tracy, 2010, p. 845). Hence the research might potentially be generalisable through the transferability of findings to

other settings such as professional carers, centred around ideas for developing self-compassion and generating a self-permission to practise self-care.

My dual position as both researcher and intervention facilitator may be seen as a limitation. Whilst there may be debates about the ethics of adopting a dual role in research (e.g. Fleet et al., 2016) I consider that the opportunities this fostered in terms of building trust, connection and understanding with participants was valuable and as outlined in Chapter 4 **section 4.3** the ethical considerations of this position were maintained throughout the research. This is a predominantly qualitive study and subjectivity is valued in the qualitative paradigm (Braun & Clarke, 2013) and objectivity seen as a futile goal (Sparkes & Smith, 2013). Throughout the study I have adopted a reflexive approach in order to maintain the trustworthiness and integrity of the research which, as Finlay (2002) describes, "encompasses continual evaluation of subjective responses, intersubjective dynamics, and the research process itself" (p. 532). I believe I have demonstrated this through the whole of the thesis. The findings will undoubtedly have been influenced by my values, personal and professional history, assumptions, sexual orientation, gender and ethnicity to name but a few of the influences on the findings. To establish credibility in the conduct of this research I have shown reflexivity through critically reflecting on the data and my role in producing the data; I have been explicit about my researcher position and transparent about the conduct of the reflexive TA. The findings show that I have included negative comments made by participants, so I do not consider that I adopted an overly positive interpretation of the data.

It is impossible nor is it desirable in qualitative research to completely remove any researcher influence; my own experience of both being a Carer and a practitioner of MSC has added a nuance to the analysis. As the findings from both Phases demonstrated, my presence as facilitator/researcher of the intervention has played a part in participants' experience of the programme and at times during the analysis it was uncomfortable to acknowledge the significance of the relationship between myself and participants. However, this could also be considered a strength as participants sufficiently trusted me to share not only their experiences of being a Carer but also their experiences of the intersection of caring, self-compassion and self-care.

Like much of the carer research (Henwood et al., 2017) this study was not longitudinal. Hence the long-term impact of a brief self-compassion intervention could not be assessed and is an area for further research. The difficulty though is that for some Carers the intense period of caring and association with palliative care services can be relatively short in nature so that longitudinal results may be affected by the death of the Caree. For other Carers with a longer caring trajectory then a longitudinal study would undoubtedly illuminate the area further.

Participants in both phases of the study made active choices to participate in a self-compassion/self-care intervention so it may be that they were already predisposed to learning about self-compassion, which may have resulted in them being more open to embodying concepts and viewing the intervention in a positive light.

Some participants had prior meditation experience and it is unclear what impact this had on their ability to engage with the content of iCare-online; it may have resulted in an easier familiarisation with the programme material and thus inflated the findings. Yet as all participants reported positive changes in all outcome measures regardless of prior meditation experience it appears that iCare-online offered additional benefits to that gained through meditation.

No account was made of participants' technical literacy and it is likely that those Carers who felt that they were insufficiently technically literate excluded themselves from participation on the grounds that the intervention was delivered online. Additionally, a lack of suitable equipment (no smart phone, tablet or home computer) may have been a barrier to participation. This latter point may mean that economically disadvantaged Carers were also excluded from the study.

8.10.2 Future Research Opportunities

To deepen knowledge and understanding of the study field future research might consider the following specific areas:

- Whilst a longitudinal study may be difficult because of the challenges involved with researching an individual caring for someone with an uncertain prognosis and whose condition could deteriorate at any time, it would be useful to explore the impact of a brief self-compassion intervention over a three or six month period beyond completion of the intervention. This would provide some understanding of whether self-compassion as it relates to Carers is sustained over a longer period than that assessed in the present study.

- The present study did not separate out Carers of those with a longer illness trajectory (e.g. dementia) from those in the terminal phase of an illness (that is those expected to die within the next 12 months). Nor did it differentiate between those participants who had been caring for shorter durations, say less than a year, and those that had been caring for longer periods. It could be that Carers may respond differently to a self-compassion intervention depending upon either the length of time spent caring or the demands of caring for someone with a specific illness with its particular characteristics e.g. dementia compared to MND compared to end stage cancer. The impact of a brief self-compassion intervention may vary depending upon length of time spent as a Carer and the Caree illness, so future research could focus on targeting specific categories of Carer.

- Given that all participants across both Phases of the study made mention of self-care, the research could be furthered by introducing additional self-report measures that captured levels of self-care before and after a brief self-compassion intervention, such as the recently developed personal Self-Care Practices Scale (Lee, Miller, & Bride, 2019; Pope et al., 2017) or Mindful Self-Care Scale (Cook-Cottone & Guyker, 2018).

- The findings indicated that Phase Two participants reported changes in their approach to caring for the Caree after completing iCare-online. Future research could including the use of an outcome measure that could assess changes in

compassion for others (e.g. Pommier, Neff, & Tóth-Király, 2020; Strauss et al., 2016).

- The facilitator's *loving connected presence* is seen as influencing participants' experience of iCare-online enhanced through personalised email feedback. It would be interesting to investigate how important this is to participants motivation and experience of an online-self-compassion intervention by removing the personalised feedback element.

- Participants in both Phases of the study exhibited signs of distress as measured by DASS at the commencement of iCare/-online. It may be that Carers with lower levels of distress would not be motivated to stick with a self-compassion intervention or would not benefit from it. Assessing Carers for levels of distress at the commencement of a self-compassion intervention and afterwards might indicate whether such an intervention is only useful for those who are, as described in Chapter Seven, 'teetering on the edge'. Findings from such research could influence whether a brief self-compassion intervention could form part of a tailored approach for Carers rather than a blanket, one size fits all approach.

- Blended approaches to delivering therapy, combining face to face and online therapy, are increasing with some positive results (Krieger et al., 2019; Wentzel, van der Vaart, Bohlmeijer, & van Gemert-Pijnen, 2016). Further research could adopt such an approach to an online self-compassion intervention, to include a face to face component with a facilitator before a move to the online delivery (with or without personalised feedback) and ending with a follow up face to face component. Alternatively, the face to face component could include a group meeting with fellow Carers before a move to an online delivery, to be followed by a further group meeting after the completion of the programme. It would be interesting to see if such blended approaches would be attractive to Carers. Carers may find a face to face element is helpful in reducing isolation through meeting others in a similar situation and developing connection with the

facilitator with less pressure to meet the fixed time commitment of a full group delivery.

- Some participants were receiving concurrent counselling during their participation in iCare-online; it could be that developing self-compassion alongside counselling could positively affect counselling outcomes (Krieger et al., 2019) and this could be an area worthy of exploration.

- As a self-funded researcher resources were limited. A more sophisticated online intervention e.g. including the development of an app and/or automated reminders to encourage self-compassion or a more interactive and advanced web-based programme, could be more impactful and remove some of the technological difficulties participants encountered.

- iCare-online was designed for time-pressed Carers but it has applicability to other groups of carers who similarly have busy lives dominated by caring responsibilities, such as those caring for others with chronic illness, frailty or learning disabilities. A brief online self-compassion intervention could also be of interest to time pressed professional carers such as health-care professionals, therapists, social workers or teachers. The utility and value of translating such a brief self-compassion intervention to these communities is worthy of further investigation.

- Male Carers were underrepresented in the study. Promotional material for a self-compassion intervention could be specifically targeted at male Carers with less emphasis on the term self-compassion but using more strength-building language to see if this attracts more male Carers. The actual word 'self-compassion' may lack clarity of meaning for some or at worse could conjure "images of caftans, well meaning people and talking sticks" (Roger, personal communication 7.7.20). Fear of self-compassion may be applicable to both genders so further studies could employ different versions of promotional material, some foregrounding the term self-compassion other versions

promoting resilience and strength building, to see whether different response rates are achieved across genders.

- Specialist cultural and media advice could be sought to help construct recruitment material and identify distribution avenues best suited to target 'hidden Carers' such as older Carers, those from Black and minority ethnic groups or those in lesbian, gay, bisexual, transgender and queer relationships who do not have connections with palliative care services.

8.11 Study Strengths and Original Contribution to Knowledge

This study offers a broad and fine-tuned exploration of participants' experiences of self-compassion. This was developed from the open-ended nature of both the semi-structured interview in Phase One and the qualitative questionnaire plus participant comments received through module feedback. This differentiates the study from the predominant quantitative research which uses the SCS to assess self-compassion and which offers less explanatory power for any causal mechanism generating the outcomes from iCare-online.

The qualitative findings were illuminated by the use of SCS and DASS as outcome measures. Using only two outcome measures ensured that I avoided adopting what Harding, List, Epiphaniou, and Jones (2012) call a scattergun approach by trying to address too many outcomes over the short period of the intervention. This was both a pragmatic decision based on a desire to not over-burden the participants given the demands already made on their time and a reasoned decision. The outcome measures used targeted the areas I felt important to address, namely changes in self-compassion and psychological well-being. However, as I was relying on self-report measures for the quantitative data there is the possibility that those findings could have been affected by socially desirable responding.

Unlike some studies where there can be some time lag between completing an intervention and then collecting data I was collecting qualitative data all through Phase

Two of the study via the module feedback. The qualitative questionnaire and outcome measures were generally completed two weeks after completing iCare-online such that participants' responses would be relatively fresh and enhance recall of their experience of the programme but allowing some distance to aid reflection.

Participants were caring for Carees with a variety of illnesses. The heterogeneity of illnesses across the two studies could be considered a strength in that a self-compassion intervention appears to be of benefit to a Carer regardless of the type of diagnosis their Caree has received.

All doctoral research requires that the researcher identifies how a study contributes new knowledge, in this instance to the field of self-compassion and Carers (Phillips & Pugh, 2015; Silverman, 2017). This study provides a significant and unique contribution to the minimal body of research on self-compassion and its relationship with self-care of Carers. I highlight below the specific original contributions to knowledge generated from this research:

- Self-compassion literature as it relates to Carers is scarce (see Chapter 2 **section 2.6.4**) and research into mindful self-compassion for Carers (the foundation of the iCare intervention) is absent. Qualitative research is also lacking more generally in the self-compassion field. In 2015 Kristin Neff commented personally to me about the need for qualitative research in the self-compassion arena. Little seems to have changed since then. Thus this study adds not only to the limited knowledge about participant experience of mindful self-compassion as conceived by Neff and Germer (Neff & Germer, 2018; Neff, 2003b; Neff & Germer, 2013) it makes a novel contribution by offering insight into how a brief self-compassion intervention is experienced by Carers. The qualitative findings present a discerning, nuanced understanding of the operation of self-compassion as it relates to Carers and answers the call for a deeper understanding that Bluth and Neff (2018) make:

> *It will be important as we move forward to have a deeper understanding of how self-compassion functions and facilitates the alleviation of suffering* (p. 607)

- Researchers call for interventions to be developed to help Carers with self-care (e.g. Applebaum et al., 2014; Dionne-Odom et al., 2017; Pope et al., 2017) but none actually propose *how* these may be constituted. iCare-online is one such intervention that could address that gap. Mills et al. (2018b) point to the connection between self-compassion and self-care when they suggest that through self-compassion, becoming vulnerable and recognising common humanity, self-compassion facilitates self-care (p. 9). This is further supported by their correlational study (Mills et al., 2018a) which pointed to a significant association between self-compassion and self-care ability. The difficulty with both studies is that they relate to palliative healthcare professionals and not Carers and do not examine methods of increasing self-compassion. The findings from the present study contribute new knowledge by pointing to a connection between increasing self-compassion and conscious self-care in Carers and providing a method for increasing self-compassion.

- This study offers a new conceptualisation of Carer self-care, linking developing Carer self-compassion with a conscious self-care, recognising the key aspect of inner permission to practise self-care and an attitudinal element of self-kindness. This conceptualisation may be useful to those working with Carers in addressing their well-being as it may help to frame supportive questions around self-care as it pertains to Carers. This involves moving away from a self-care activity-based focus to exploring ways of developing kindlier self-talk and ultimately encouraging the self-permission aspect of Carer self-care.

- This is the first study to explore the impact of a brief *online* self-compassion intervention for Carers. Not only is there no research, at the time of writing, into a self-compassion based intervention for Carers (regardless of the underpinning compassion theory) whether this be in a brief or longer format, there are no

studies of an online delivery of a brief self-compassion based intervention for Carers. Hence this study offers the first exploration of participant experiences of a brief self-compassion intervention tailored to address the Carer experience.

- This study highlighted the importance of permission in the role of Carer self-compassion and self-care, an area that is under-researched. Carers require permission to practise self-care and become more self-compassionate. Permission can take the form of being given permission by a trusted other who often is a healthcare practitioner, which emphasises the importance of the role that healthcare practitioners play in fostering Carer permission to practise self-care. Based upon the findings, such encouragement and permission should be forthcoming on the basis that the Carer is valued as an individual, not as a function and adjunct to the Caree or as a cost-saving to a national health service. The research also indicated that permission can take the form of a self-permission developed through becoming more self-compassionate, a new understanding.

- Carers are time poor and have unpredictable demands placed upon them dependent upon the health of their Caree. As such this study showed the value of a flexible delivery of an online self-compassion intervention. Carers benefit from taking a more leisurely approach to bringing self-compassion into their lives. A fixed period within which an intervention must be completed has the potential of unnecessarily pressurising Carers. Allowing a lengthy period for Carers to embed self-compassion is also an important finding.

- This study highlighted the importance of participants experiencing a *loving connected presence*. Personalised email support throughout iCare-online for participants, rather than generic, automated responses to module feedback or queries, is a vital part of establishing this presence. This engagement with participants was particularly valued and as such is identified as an essential

component of a brief online self-compassion intervention, which has not been seen in other online self-compassion-based interventions.

8.12 Recommendations and Implications for Practice

Based on the findings from this study I make the following recommendations and highlight implications for practice across three areas:

8.12.1 Healthcare Practitioners and Palliative Care providers

The findings show that the role of professionals (e.g. doctors, nurses, occupational therapists, social workers, counsellors) in encouraging and legitimising Carer needs is particularly important. As explained above participants needed a 'trusted other' to encourage them to participate in iCare-online to overcome the barriers outlined. In practice this will require a gentle, sustained and repeated encouragement to Carers to value their own needs, before they will start to meet those needs. Carers may need to hear the message several times before they take heed of it, and it may be that Carers vary when they are prepared to accept support dependent upon where a Carer is in their caring journey (Köhle et al., 2017).

This encouragement, I posit, needs to be authentic to be convincing – the professional must have a genuine belief in the value of self-care and self-compassion for themselves first and then for the Carer. It is of concern that, for example, Andrews et al. (2020), found that nurses could not give themselves permission to practise self-care; if they are unable to allow themselves to meet their own needs then my worry would be that any message to Carers risks becoming a trite, bland statement with echoes of 'do as I say' rather than 'do as I do'. Additionally, directives about the value of self-care should be presented within a prizing and 'seeing' of the Carer as an individual not merely as aide to the Caree or as a cost-saving to health and social care budgets.

The sooner a Carer is offered an intervention, such as iCare-online, on their caring journey the increased possibility it has of sustaining the Carer and building resilience for the challenges inherent in caring for someone with a life-limiting illness. In my clinical experience, too often it seems that hospice contact, with both a Caree and their

Carer, is quite late in the illness trajectory such that interventions to support Carers may be offered at a time when the Carer is overwhelmed by the deteriorating condition of the Caree. If an intervention was offered earlier in the caring journey, perhaps even when a Caree is still receiving active rather than palliative treatment within a hospital setting, then this might be a more opportune time for the benefits of a self-compassion intervention to take effect.

In light of comments made by Ugalde et al. (2019) regarding the paucity of studies commenting on ways "to maximise the potential for interventions to be successfully implemented" (p. 698), I will briefly summarise some practical matters to be considered if iCare was to be implemented in an organisational setting, in either the face to face or online version. The facilitator of iCare, or a similar self-compassion intervention, should be skilled, therapeutic and trained in the practice of mindful self-compassion (in the case of iCare). This individual should be someone who will not be overwhelmed by deep expressions of emotional pain and who ideally understands the role of the Carer. The findings from both Phases of the study revealed the power and intensity of Carers' feelings and a facilitator needs to be able to hold these emotions, to allow Carers to be heard as well as reflecting on the aspects of self-compassion that the Carer can call upon for support. A particular skill set is required to work with online module feedback, a skill that I had to develop drawing upon my therapeutic training as a counsellor and as a trained MSC teacher; it was time-consuming to monitor individual progress though iCare-online and to respond sensitively to feedback. As responses were there for participants to re-read rather than in the moment comments, as in the face to face delivery, it was important that my comments were sufficiently skilful in terms of theoretical content (from an MSC teacher perspective) whilst also couched in a warm engaging tone.

Organisations offering support to Carers e.g. hospices or specific illness charities, should not consider an online intervention, such as iCare-online, to be necessarily more cost-effective compared with one to one counselling or seen as a way of reducing staff costs compared with counselling or another psychoeducation intervention. Management should be aware that it is time-consuming for a facilitator to offer the personalised

support and monitor participant progress through an intervention, although unlikely to be as time consuming as offering four sessions of therapy per Carer. Other costs that need to be considered are the costs of training the facilitator who, in the case of iCare-online, needs to be a trained teacher of MSC with their own well-established self-compassion practice. This training is expensive. However, once a facilitator is trained then there would be the capacity to explore different delivery modes for a brief intervention, including face to face group work. In the future it may be possible to offer cost effective training to therapeutically minded individuals in facilitating a specific online self-compassion intervention, without requiring the full MSC teacher training.

Gains for any organisation introducing a brief self-compassion intervention for Carers (face to face or online) include providing a targeted intervention that appears to meet Carers' needs regarding content acceptability and usability and has beneficial outcomes for Carers. Ultimately such an intervention could have long term implications in reducing the need for social or psychological input through e.g. counselling, both during the caring period and after into bereavement. This is an area that requires further research.

8.12.2. Therapeutic Practice and Training

Counsellors or psychotherapists, especially those who are based within hospices or oncology departments, working with clients who are Carers could benefit from holding an awareness of the need to gently challenge resistance in Carers to recognising their own unmet needs and to becoming more self-compassionate. Practitioners need to be aware of the social discourse around the acceptability of self-compassion (Andrews, 2018; Campion & Glover, 2017) and the barriers that Carers are likely to erect in the face of being encouraged to practise self-compassion and self-care. Additionally, as Campion and Glover (2017) comment, "it seems vital that we 'practise what we preach', becoming versed in extending compassion towards ourselves before attempting to instil it in others" (p. 1107). Authenticity is key. When working with all clients including Carers, it is not enough to pay lip service to self-care and self-compassion if, as the practitioner, this is something that you avoid for yourself. To struggle with these concepts is to be

human; to ignore or deny them in yourself but expect those you work with to embody these concepts is inauthentic and clients will likely sense this.

The British Association for Counselling and Psychotherapy, one of the major professional associations for those in the counselling profession, recommends in its Ethical Framework that members practise self-care in order to take responsibility for their own well-being so as to maintain good practice (British Association for Counselling & Psychotherapy, 2018a, p. 27 section 91). As this is an ethical obligation placed on counsellors and psychotherapists, BACP accredited training courses will likely encourage trainees to develop self-care strategies and plans as part of becoming an ethical practitioner. I would encourage all trainers to explore students' attitudes to self-care and self-compassion given the prevailing negative attitudes around self-compassion and self-care, especially amongst those in the caring professions, and to consider ways to develop the self-legitimisation of their own needs perhaps through threading self-compassion throughout the curriculum, if not actively offering brief training in self-compassion.

Whilst iCare/iCare-online was not established as a pluralistic intervention (Cooper & McLeod, 2011) it has the potential to be used as part of a pluralistic approach to counselling and psychotherapy based on the needs of the client, particularly those who have heavy caring burdens, especially those caring for loved ones with a life-limiting illness.

8.12.3 Teachers and Researchers of MSC

Teachers of MSC might like to take note of the cyclical model of Carer self-compassion. Whilst this is applicable to Carers, maintaining an awareness of the permission-giving aspects of iCare and the development of 'conscious self-care' seem to be fundamental aspects of self-compassion for Carers which may be transferable to wider carer populations. Teachers may benefit from holding an awareness of these features and seek to gently strengthen and promote these facets in their class members.

Future self-compassion research with Carers should emphasise the value of developing relationships between the researcher and relevant healthcare practitioners and support workers. This could permit in-depth explanations of the research including the potential value to Carers and the building of trust in the intervention facilitator in order that such professionals can promote the research to Carers. This is particularly important given the role healthcare practitioners appear to play in endorsing self-care and self-compassion interventions to Carers. Passive recruitment material such as flyers and posters does not appear to engage potential participants.

8.13 Summary

This Chapter is divided into two parts. Part One presented a summary of the findings from Phases One and Two of the study providing an overview of the key aspects of the qualitative and quantitative data. In Part Two of this Chapter the findings were considered in relation to three significant areas and contextualised by relevant literature. A causal mechanism was proffered which encompassed a cyclical model of Carer self-compassion. Contributions to knowledge were summarised together with the strengths and limitations of the research. Recommendations and implications for practice were outlined and suggestions made for further research.

In the next and final Chapter, I address the research question set out in Chapter One and present my final reflections and thoughts about the research.

Chapter Nine: Final Reflections

9.1 Introduction

In this final chapter I provide an answer to the research question and offer a few final reflections on my research journey.

9.2 Answering the Research Question

In Chapter One I stated the research question as:

What is the impact of a brief online self-compassion programme (iCare-online) on carers of those with a life-limiting or terminal illness?

To answer this research question, I adopted a two phased approach to the research. In Phase One of the study I delivered a face to face delivery of iCare to nine Carers to better understand how Carers perceived the content of this programme and to what extent they reported on benefits, if any, from implementing some of the practices and approaches in their lives. iCare in the face to face version was generally well received and the findings highlighted certain aspects of iCare that could be emphasised in the online delivery. These included ensuring that the online material was authentic, warm and, as best as it could, offered some sense of connection with participants; that shorter practices were likely to be more easily accessible to Carers and that the encouragement to pick and choose practices and to go at your own pace rather than focus on a short fixed delivery was to be encouraged. In this way the findings from Phase One influenced the creation of iCare-online.

The online version of iCare took some time to develop as I had to build my own technological competencies and identify a suitable platform to host iCare-online. Unlike Phase One, recruitment to Phase Two was difficult and protracted. Despite recruiting widely and the research generally being warmly received by several gatekeepers particularly hospices, participant numbers for Phase Two were nowhere near as high as anticipated. Some forms of recruitment yielded no response at all such as Facebook

groups or local member groups of national illness charities. It was only as I completed the literature review (Chapter Two) that I began to understand that recruitment material was overly fixated on the concept of 'carer' not a term that Carers necessarily identify with.

The findings from Phase Two answer the research question in the following respects:

- Those participants who completed iCare-online reported positive changes in their well-being, self-acceptance and their attitude to prioritising their own self-care. These changes were reflected in the outcome measures which captured large increases in global self-compassion and marked reductions in levels of depression, anxiety and stress.

- Carers seem to need a trusted other to endorse the value of an online self-compassion intervention and to give them permission to undertake an intervention that is focused on their self-care rather than their Caree's needs. Without such permission the barriers that Carers face (ambivalence towards technology, lack of time and possibly a wariness of the term 'self-compassion') appear to make an online intervention unattractive.

- In addition to requiring permission to participate in an online self-compassion intervention, Carers also seem to need to be struggling in their caring role to motivate participation; those Carers who evidence less distress may potentially be less likely to be interested in such an intervention.

9.3 Researcher Final Reflections

I started my research journey excited at the prospect of exploring in depth the impact developing self-compassion may have on Carers and in doing so to take an established programme and amend it until it was in package that I thought could meet Carers' needs. It was a privilege to sit with nine Carers and teach them something that I thought might be useful to them and then to hear how they had woven some of the concepts into their lives to support themselves. So, it was painful and demotivating to discover

the lack of interest in an online delivery of the same programme – surely this was what all Carers' needed - an online programme delivered directly into their own home placing control over access firmly in their hands? Why such little interest? At the end of this research journey I now know so much more about the Carer position, their needs and the barriers they must overcome in order to access supportive interventions, especially those delivered online. I can see how naïve I was in thinking that an online intervention could be a panacea for many of their ills.

As the study progressed, I found myself developing an awareness of the social discourse around the Carer position and began to see the marginalisation of the taken-for granted Carer. This was compounded by a distinct lack of interest in my research at counsellor research conferences. Carers, and by association me, were hidden and undervalued. Their position epitomised by their treatment during the current Covid-19 pandemic. My fury started building and has not abated. Mostly it is centred on the Carer position, but of course I have a personal attachment to my research and my past experiences as a Carer fuel this fury. I cannot remove the personal from the research nor would I seek to do so. This has helped generate what Hubbard, Backett-Milburn, and Kemmer (2001) describe as 'emotionally sensed knowledge', that is "the researcher uses their emotion in the field, in discussions with colleagues, during personal reflections and when analysing the data, to gain insight and give meaning to their interpretations" (p. 121). This I have certainly done.

9.4 Personal Reflexivity 'I' positions

In Chapter Three, **section 3.9**, I commented on both functional and personal reflexivity and referred to the adoption of 'I' positions in relation to the latter. These are summarised here as follows:

The Carer/Cared for I representing my experiences as a Carer/carer and someone who has received care following injuries incurred in the middle of the PhD journey.

The Angry I which developed as I moved through my research and I became more finely attuned to the pain and suffering of Carers and the general lack of interest in the wider public in Carers.

The Snickers Bar I encapsulating my self-doubt which has accompanied me throughout the research journey.

The Detached I uncovered towards the end of the research journey; an I position of detachment from those closest to me, as working with Carers reminds me that I too could become another Carer again and my resistance to that fate, resulting in numbing and a quiet closing down.

I now explore these 'I' positions in greater depth and refer to the impact on the research of these positions.

The Carer /Cared-for I

As referred to in the Introduction I have been a Carer more than once and was actively caring during my abortive first PhD registration. In my work as a counsellor, I am a carer too and as a wife, mother, sister, friend I continue to be a carer of sorts. During the period of this study I have become a carer of a chronically ill adult-child, who now lives at home and one who, despite all my best efforts, has so far failed to recover their health. This has given me some insight into the despair and hopelessness that Carers feel at the intractability of their Caree's condition.

In turn, I have also been cared for. During the period of the study I suffered two separate injuries, resulting in hospitalisation, operations and several months lying on a sofa immobile, totally dependent upon others to care for me. Witnessing my own carer in action and the stresses my incapacity brought him I could see how difficult it was for him to allow himself to look after himself despite encouragement to do so.

These experiences sensitised me to both Carer and Caree positions which enhanced both data collection and data analysis. The Carer/Cared-for I explores what Berger

(2015) describes as "reflexivity when studying the familiar" (p.222). Participants in both phases knew that I had an insider position (Dwyer & Buckle, 2009; Hellawell, 2006), not at the recruitment stage but during the delivery of iCare/iCare-online as at times I did make reference to using some of the practices in my own caring as a way of illustrating how practices and approaches can be utilised. Yet I consider that I managed to maintain both an insider and an outsider perspective allowing for both an empathic understanding and a detached position when undertaking the analysis (Hellawell, 2006).

The Angry I

The Angry I emerged later in the research as I became more aware of how Carers are perceived by wider society. Willig (2013) suggests that personal reflexivity, inter alia, requires the researcher to think about how they may have been impacted and even changed by the research as an individual and as a researcher. As a researcher I was influenced by the strength of one participant's' vociferous calls for better treatment of Carers. Whilst this heightened my awareness of the Carer plight it also held the potential of my assuming that that participant spoke for all the other Carers in the study. It took me some time to appreciate that I needed to look for what was *not* being said in the findings and was a salutary lesson in developing my researcher skills.

As an individual I have been affected by the participants' narratives, at times deeply moved by both their caring experiences and the impact self-kindness and self-compassion has brought to their lives. I have developed a heightened critical awareness of media coverage of Carers and am sensitive to stories of quiet heroism without any recognition of the lack of support available to Carers or carers. I find I am quickly moved to angry responses to radio items or newspaper coverage that ignores Carers or expects more from this unpaid sector. The Angry I will propel me to publish my research and, introvert that I am, to seek opportunities to speak about my research.

The Snickers Bar I

A Snickers bar became a metaphor my principal supervisor and I used to represent my self-doubt and frequent adoption of an external locus of evaluation. As I recall from one

supervisory meeting towards the latter stages of the research, I was admonished to stop putting myself and my research 'down' and to stop my self-deprecating stance on the basis that if my supervisor had a Snickers bar for every time I did this or failed to own my academic authority, then by the time I submitted my thesis he would be clinically obese. Whilst this comment made us laugh, he had succinctly captured the self-doubt woven through my research journey.

This was abundantly clear from many journal entries when I wrestled with over-whelm and questioning of the value of a self-compassion intervention, my ability to deliver it in an authentic and meaningful way and of my ability to ethically and credibly research it. Self-doubt infiltrates most of my research, the Snickers bar sitting on the table between my supervisor and myself, moving closer towards him or back towards me, depending on how confident I am feeling. Certainly, in the early days of my research journey at Chester my supervisor could have metaphorically put on a few pounds as I questioned the value of the intervention I was offering to participants in Phase One.

Figure 4

Snickers Bar

The Snickers Bar I was soothed and ameliorated when participants offered positive comments about their experience of iCare/iCare-online and thus, it was important to be aware of my attachment to participant outcomes. Hence, I have sought throughout my analyses to contain the Snickers Bar I less my unconscious search for affirmation closed my eyes to any negative comments or hesitations in participant responses. Additionally, as someone trained in self-compassion and who formally practises MSC material, it was important to maintain awareness that I might unconsciously evoke

responses from participants that mirrored my commitment to self-compassion. Whilst it could be argued, particularly in Phase One, when a personal face to face relationship was developed with participants, that in their research interviews participants may have gone out of their way to please me and support me by only feeding back about their positive experiences of iCare, I was clear about stressing the need to hear both good and bad experiences in order to better shape a future version of iCare.

In Phase Two participants were asked in the post iCare-online questionnaire what 'didn't work' for them and how iCare could be improved to ensure that participants were aware that criticisms were welcomed. In fact, through both iterations of iCare I attempted to be as open as possible with participants – expressing a genuine interest about what didn't work or was not useful; participants were advised, as in Phase One, that not all of the content would speak to them and they were to pick and choose which parts they liked and wanted to practise with and reject the rest. This is what participants did and were comfortable to tell me this.

The Snickers Bar I can also be seen in my attention to detail and thoroughness in conducting this research e.g. questioning my analytic procedures, reviewing, checking analyses, referring back to procedural guidelines and being prepared to redo analyses and rewrite findings if they did not sufficiently capture the data. Whilst this may on occasions have veered towards 'over-egging the pudding', I consider it has added to the credibility of the study.

However, the Snickers Bar I persisted (Research Journal entry 4.6.19 *V low mood; … Can't be bothered with anything; bored, tired, low energy. Guess with lack of interest* [from potential Phase Two participants] *feeling what's the point to my research. …really what is the point*) and continues to sap my confidence from time to time and the Snickers bar moves across the table toward my supervisor, although in these last few months less frequently. Yet right at the end of the write up there it appears again (Research Journal entry 4.7.20 *Hilarious - writing up Strengths and Limitations. 3.5 sides of notecards on Limitations and not a card for Strengths!*).

And yes, there is a dissonance between being a teacher/researcher of self-compassion and the apparent lack of self-kindness I offer myself when I feel the need to offer another Snickers bar up!

The Detached I

Our research has the potential to touch vulnerable places within ourselves, particularly in the case of qualitative research when we bring so much of ourselves to the process. Sampson, Bloor, and Fincham (2008) suggest that research, in addition to stirring up 'painful memories', can provoke "new emotional responses of anxiety, concern, or empathic pain" (p. 926) and so it was for me. It has taken towards the end of the study to identify how I have developed a detached, cooler emotional position vis-à-vis my family. It is not memories that feed the detachment but rather fear of the future. Immersion in the world of Carers coupled with extensive hospice experience reminds me of what I could face, as reflected in the following Research Journal Entry 29.2.20 *The fear, amplified by my research, that I have of becoming (ano) carer …What could I face? Has this [research] detached me from [husband]? Have I withdrawn to protect myself? In some ways has the research contaminated me? I don't want to feel the pain my participants have/are experiencing …*

I am aware that in some small part I have withdrawn into the research and, yes, withdrawn to a certain extent as a carer to the family. I appreciate that I am privileged to have been able to make this choice. I continue to be in awe of, and moved by the quiet, determined courage that my participants show in their devoted care and I am left questioning whether I could be as brave or courageous as them should I be called upon to become a Carer. Time will tell. Time will also tell whether, as I move out of the intense period of study, the sense of detachment will ease. I recognise that self-compassion is called for.

9.5 Summary

These 'I' positions point to the emotional labour involved in undertaking qualitative research (Creek, 2012; Hubbard et al., 2001; Sampson et al., 2008). It is not for the faint-hearted if fully embraced. My research journey has been challenging, invigorating,

exhausting and, yes, joyful. I am passionate about research and have loved the wrestling and tussling involved, except of course when I hated it. As I write these final words I can begin to see my progression as a researcher from timid novice to a slightly scarred, more aware researcher who can reflect on where she has come from and the lessons learned along the way but can see how much more there is to learn.

And finally …

In Chapter Eight I cited Bluth and Neff (2018) who stated:

> *It will be important as we move forward to have a deeper understanding of how self-compassion functions and facilitates the alleviation of suffering**, so that this body of research can ultimately be used to help people learn to thrive in the midst of their struggles and find inner happiness*** (p. 607, emphasis added)

Certainly this study aimed to illuminate how self-compassion could help Carers 'thrive' as best they can despite the pain of their situation; whether developing self-compassion leads to inner happiness for Carers in the face of loss and the day to day pressures of caring may be a step too far. However, I will continue to offer self-compassion trainings in a variety of formats to Carers/carers embedding the learnings from this study as the power of treating yourself with kindness should not be underestimated.

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Appendix 1: List of research databases/search engines and search terms

Databases researched

Search Engine	Web Site	Database
University of Chester		PsyARTICLES PsychBOOKS PsyINFO PubMED CINAHL PLUS MEDLINE
Keele University		Library Search
Google Scholar	https://scholar.google.com/	
British Library EThOS e-theses online service	https://ethos.bl.uk/Home.do	

The table below details the range of search terms and search strings used to research the databases and web sites in the table above.

Search terms and search strings used in literature review

'carer', 'caregiver', 'self-compassion', 'intervention, 'palliative', 'life-limiting', 'online' or 'mindfulness'	unmet needs AND carers OR caregivers OR relatives OR family members AND life limiting OR palliative OR end of life OR terminal illness AND self-care
Barriers AND 2. self-compassion OR kind* or empath* OR compassion* OR self-care	Carers OR caregivers OR relatives OR family members AND 2. Life limiting OR palliative OR end of life OR terminal illness

3. Carers OR caregivers OR relatives OR family members AND 4. Life limiting OR palliative OR end of life OR terminal illness 5. Barriers OR obstacles OR challenges OR difficulties OR issues 6. support 7. stigma OR self-stigma OR "public stigma" 8. self-care	3. mindful self-compassion 4. mindfulness OR compassion OR meditation 5. short-form or brief 6. online OR web-based OR internet
1. Unmet needs AND 2. Carers OR caregivers OR relatives OR family members AND 3. Life limiting OR palliative OR end of life OR terminal illness 4. positive aspects of caregiving 5. self-care 6.burnout OR compassion fatigue OR secondary traumatic stress OR vicarious traumati*ation or emotional contagion 8. well being OR well-being OR wellbeing 9. self-efficacy 10. resilience OR resiliency OR resilient	1. (self-compassion OR kind* or empath* OR compassion* OR resilience OR strength OR mindful*) AND (care* OR famil*) AND (online OR on-line OR educat* OR *educat* OR course OR instruct* OR learn* OR teach* OR coach* OR tuition OR stud* OR therap* OR counsel* OR "skills training" OR intervent*) 2. Carers OR caregivers OR family members OR relatives AND Life-limiting OR palliative OR end of life OR terminal illness AND Intervention 3. Carers OR caregivers OR family members OR relatives AND Life-limiting OR palliative OR end of life OR terminal illness

	AND self-compassion or self compassion 4. family OR relatives AND Life-limiting OR palliative OR end of life OR terminal illness AND self-compassion or self compassion
Carers AND Psychological Distress; Care* AND psychological distress AND life limiting illness; Care* AND depression anxiety; coping; quality of life; life limiting illness; terminal illness; Dementia care* AND anxiety AND depression; Care* AND liver failure AND depression; Care* AND motor neurone disease AND depression	Care* burden AND palliative AND cancer Care* burden AND palliative AND cancer AND quality of life Care* burden AND terminal AND cancer caregiver* AND quality of life
self-compassion AND permission AND self-care	Mindful self-compassion AND permission AND self-care
Mindful self-compassion OR MSC AND permission AND self-care	

Appendix 2: Ethical Approval Phases One and Two

University of Chester

Mrs C. Diggory
[redacted]

Department of Social and Political Science

sps@chester.ac.uk
Direct Line 01244 512040

23rd January 2017

Dear Catherine

RE: ETHICS APPLICATION

Thank you for submitting your amendments to your ethics application for the following study:

Exploring the Mechanisms of Self-Compassion Through the Life Experience and Perceptions of Carers of Those With a Life Limiting or Palliative Diagnosis

We are pleased to inform you that the required amendments have been satisfactorily completed. Ethical approval has now been granted for you by Chair's action. You may now proceed with your research, subject to appropriate consultation with your supervisor.

We wish you all the best in conducting this study.

Yours sincerely

Dr Peter Cox
Chair of Ethics Committee

Catherine Diggory
[redacted]

University of Chester

Department of Social and Political Science

sps@chester.ac.uk
Direct Line 01244 512040

12th November 2018

Dear Catherine

RE: ETHICS APPLICATION

The Department of Social and Political Science Ethics Committee has considered your application for ethical approval for your research for the following study:

Researching an online mindfulness and self-compassion programme (iCare) for carers of those of those with a life limiting or palliative diagnosis

We are pleased to inform you that the committee has granted approval for you to proceed with your research. In the comments section of the returned and completed application you may find further suggestions to assist you in the conduct of the research.

We wish you all the best in conducting this study.

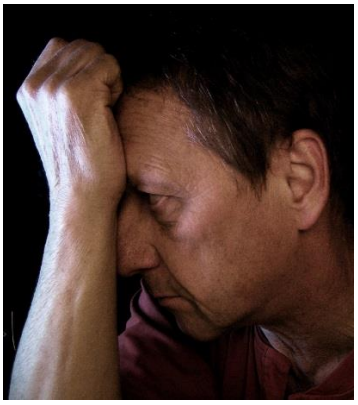
Yours sincerely

Prof. Peter Cox
Chair of Ethics Committee

Appendix 3: Recruitment Poster Phase One

University of Chester

Are you a Carer?



Do you care for someone with a life limiting illness? Would you like to learn ways of handling your stress and anxiety through participating in the iCare programme?

Would you be prepared to take part in research to help other Carers?

Being a carer of those with life limiting illness e.g. certain cancers, motor neurone disease, dementia or multiple sclerosis, can be very **stressful**. Increasing your ability to take greater care of yourself may help you to stay **resilient** and **healthy** in the face of stress.

What's **iCare**? It's a free four week programme of hourly sessions with mindfulness and self-compassion teacher Kate Diggory. You'll learn some techniques and practices to help support you as a Carer. You can find more details about what is involved in the Participant Information Sheet available here or you can go to:

www.katediggory.com/carers-research/

Appendix 4: Participant Information Sheet Phase One

Participant Information Sheet

Exploring the mechanisms of self-compassion through the experience and perceptions of Carers of those with a life limiting or palliative diagnosis.

Dear

Thank you for indicating that you are interested in taking part in this research. This Information Sheet will hopefully explain what is involved, but if you need further clarification, then please do not hesitate to contact me using the contact details below.

What is the purpose of the study?

This research is part of my doctoral thesis that I am undertaking at the University of Chester. Being a carer of those with life limiting illnesses e.g. certain cancers, motor neurone disease, dementia or multiple sclerosis, can be very stressful. Increasing carers' ability to manage their own needs and take greater care of themselves may help them to stay resilient and healthy in the face of stress. One way of developing this ability is through a mindfulness and self-compassion training programme. One such programme is called iCare. It is a four-week programme designed to develop well-being, manage stress, burnout and compassion fatigue using mindfulness and self-compassion practices.

You are being invited to participate in the iCare programme as you are a carer and I would be very interested in exploring your views on, and experience of, this programme.

Who can take part?

Anyone who is currently involved as a carer to an individual who has a life-limiting or terminal illness can participate. A life limiting illness is one that is known to shorten people's lives. These types of illnesses include, among others, heart failure, liver failure, lung disease, motor neurone disease, multiple sclerosis, dementia, HIV/Aids, certain forms of cancer, spread of cancer and recurrence of cancer that has previously responded to treatment.

A carer is someone who cares, unpaid, for a friend or family member who due to a life-limiting or terminal illness, cannot cope without their support. Caring can include:

• Practical household tasks such as cooking, cleaning, washing up, ironing, paying bills and financial management.
• Personal care such as bathing, dressing, lifting, administering medication and collecting prescriptions.
• Emotional support such as listening, offering advice and friendship

Please note if the person you care for is aged under 18, or you yourself are under the age of 18 or the person you care for has a chronic disease or disability which does not limit life expectancy then you will not be able to participate in this particular study.

What would be involved?

You will be invited to attend four weekly one hour sessions with me on a one to one basis where I will teach you some simple principles and guide you through some practices and exercises to support you. These sessions will be digitally recorded. Your written consent will be obtained through the enclosed consent form. In between sessions you will be encouraged to practise meditations and informal practices but this is not mandatory. The daily maximum practise commitment is around 20 minutes. After the programme has been completed approximately two weeks later I will arrange a time to interview you face-to-face at your convenience, or to have a SKYPE/FaceTime interview with you if that is more convenient. The interview will be digitally recorded and last no more than an hour.

The interview will be semi-structured and be focussed around the following questions:

- How did you find the iCare programme? How would you define self-compassion?
- Did anything get in the way of you becoming kinder and more self-compassionate to yourself?
- Following the end of the iCare programme what changes, if any, have you noticed in your thinking and feelings? Have you made any practical changes to your life?
- If you have noticed any changes what do you think encouraged those changes?

Once the interview is complete, the digital recording will be transcribed. Your transcript will be allocated a pseudonym or code to protect your anonymity, and any identifying features in the data will be deleted. The transcript will be emailed to you to check for accuracy and to give you an opportunity to amend or change any of the data.

Your right to withdraw without prejudice

You have every right to withdraw from the study at any stage, up to when I complete the analysis of the data. Even if you choose to withdraw from the research you will still be able to participate in the iCare programme sessions.

What are the possible disadvantages and risks of taking part?

One disadvantage of taking part in this research is the cost of your time. There is a small possibility that participating in the iCare programme or talking about your experience of it may cause upset or raise emotive issues. In these circumstances I will do my best to support you in the time we are together. I am also able to provide you with a list of therapists in your locality whom you may be able to access for support. Carers UK also have a Help and Advice line: 0808 808 7777

What are the possible benefits of taking part?

Potential benefits include the opportunity to learn new skills and practices to build your resilience and manage stress in your role as a carer. Additionally, through participation in the research you may be helping to influence future support for carers.

What if something goes wrong?

I will do everything within my ability to ensure your safety and confidentiality. However, if you are not happy with any aspect of the research process, please raise it with me. If you are still not happy, you may raise it with my Research Supervisor, Dr Andrew Reeves, at the University of Chester: https://www.chester.ac.uk/sps/staff/dr-a-reeves

If you are still unhappy with things, you may then raise it with the Dean of Faculty, Professor David Balsamo: Email: d.balsamo@chester.ac.uk

Will my taking part in the study be kept confidential, and how will my data be stored?
The fact that you are taking part in the research, and everything that you share, will remain confidential. In the unlikely event that Child Protection issues are raised, I may have to alert Social Services or Police, but otherwise, what you share will form part of the data which will be anonymised by use of a pseudonym or code. The data will be stored securely in locked premises, and kept encrypted on a password protected computer. Only I, and my Research Supervisor, will have access to the data. The data will be destroyed (shredded or electronically deleted) after 10 years, in keeping with the Data Protection Act.

What will happen to the results of the research study?
The completed research will be stored (bound and electronic) at the University of Chester. The research will be disseminated in future publications and at conferences.

What do I do now?
If after reading this Information Sheet you are interested in taking part in this research please contact either me or my research supervisor using the details below:

Researcher	Supervisor
Kate Diggory	Dr Andrew Reeves
Xxxxxx@chester.ac.uk or Mob: xxxxxxxx	xxxxxxx@chester.ac.uk
University of Chester Division of Counselling and Psychotherapy Dept. of Social and Political Science University of Chester Parkgate Road Chester CH1 4BJ	Tel xxxxx xxxxxx

Thank you for your interest in this research.

University of Chester

Consent Form

Exploring the mechanisms of self-compassion through the experience and perceptions of Carers of those with a life limiting or palliative diagnosis.

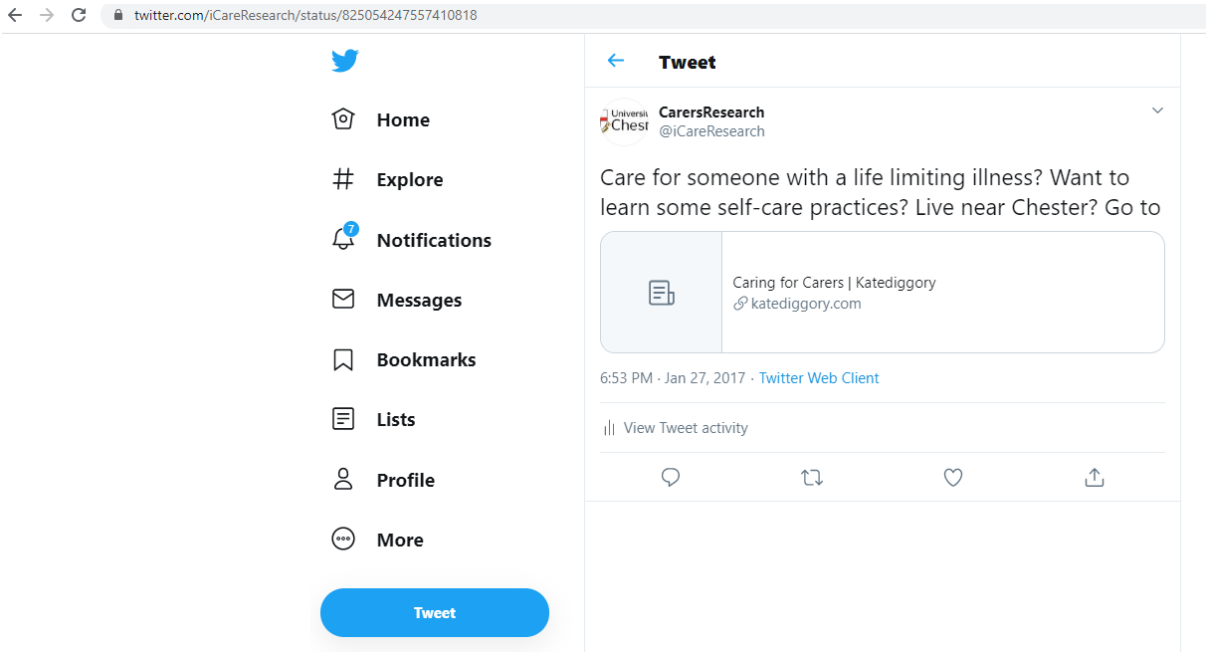
Name of Researcher: Catherine Diggory

Please initial box

1. I have read and understood the participant information sheet and have had the chance to ask questions. ☐
2. I agree to the one to one sessions and the research interview being audio recorded. ☐
3. I understand that my participation is voluntary and that I am free to withdraw at any time before the research interview has begun to be analysed, without giving any reason. ☐
4. I agree to take part in this study and have the right to withdraw from the study at any stage up to when the analysis of the research interview is completed. I understand that by withdrawing from the research, this does not affect my access to the iCare sessions, which will remain available to me. ☐
5. I understand that the data will be written up as part of a thesis and I will not be identifiable in the thesis. ☐

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Researcher	Date	Signature

Appendix 5: Pinned Tweet Phase One



Appendix 6: Consent Form Phase One

University of Chester

Consent Form

Exploring the mechanisms of self-compassion through the experience and perceptions of Carers of those with a life limiting or palliative diagnosis.

Name of Researcher: Catherine Diggory — Please initial box

1. I have read and understood the participant information sheet and have had the chance to ask questions. ☐
2. I agree to the one to one sessions and the research interview being audio recorded. ☐
3. I understand that my participation is voluntary and that I am free to withdraw at any time before the research interview has begun to be analysed, without giving any reason. ☐
4. I agree to take part in this study and have the right to withdraw from the study at any stage up to when the analysis of the research interview is completed. I understand that by withdrawing from the research, this does not affect my access to the iCare sessions, which will remain available to me. ☐
5. I understand that the data will be written up as part of a thesis and I will not be identifiable in the thesis. ☐

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Researcher	Date	Signature

Appendix 7: Interview Guide Phase One

ASK FOR CONSENT TO RECORD BEFORE START

So I think the first thing to say is whatever your experience is it is going to be really helpful, whether it is negative or positive because this is going to shape the online delivery which hopefully, one hopes, is going to reach more people one day, so there is so much to learn from your experience of the programme, so I don't want you to worry about me being offended, if you have anything negative to say.

- Having been through the iCare programme how would you now define self-compassion?
- Did anything get in the way of you becoming kinder and more self-compassionate to yourself?
- Following the end of the programme what changes, if any, have you noticed in your thinking and feelings about yourself? Have you made any [practical] changes in your life following the iCare programme?
- If you have noticed any changes what do you think encouraged those changes?
- What prompted you to sign up for the iCare programme?
- What were you hoping to get out of the programme?
- It's a couple of weeks since the programme ended, looking back over it what do you remember most about it?
- What worked for you? What didn't work for you?
- What was your biggest disappointment about the programme?
- Were there things I did that weren't helpful? Not everything will be great or will have applied to you?
- What about the words and terminology that I used?
- What hints and tips would you give me for doing this online?
- What about a Facebook group- would that have been useful?
- If another carer stopped you in the street and said tell me about the iCare programme because I might be interested in it, what would you say?

Appendix 8: Evidence of Coding

1. Example of initial, predominantly inductive coding - Phase One

	I: how would you now define self-compassion, given that's what the course is all about or the programme, what's your take on it?
Defn: permission to focus on self P2 21(see 248) Defn: recognition of carer's needs P2 21	P2: ErmI think, erm to turn the focus to me rather than the focus to [husband]; it's alright to focus on me, you know, I have needs, emotional needs.
	I: And it's okay.
Defn: giving yourself permission P2 25	P2: Yes, so it's like giving yourself permission isn't it?

Defn SC: putting self first; not feeling guilty for everything P9 148 Now everyday opportunities to practice self-care and not put it off P9 148 Permission to give herself time P9 148	P9: Putting me first, umm…not feeling guilty for little things as well as big things, so say [partner] at home sleeping and I think 'god I really want to go out and do something', I'll just go out and do it if I know she's well enough, whereas before I would have thought 'oh I'll do it tomorrow, I'll do it tomorrow. … .. normally I'd be like 'I've got to get home, I've got to get to [partner]', but I was like 'no, I'm quite enjoying this' so I gave myself more time, I just messaged [partner]and said 'still shopping, I'll be home in an hour or so', whereas before I would

More flexibility in giving herself time P9 148 Choosing not to rush back to Caree p9 148 At ease with doing things for self; surprise that likes it P9 148	have been, waited outside the dentist, seen the dentist, gone straight home, this time I kind of…feel more flexible, more…at ease with doing things for me, and I like that, I didn't think I would, the croissant doesn't think I do, but it's nice.
Defn self-compassion awareness (mindfulness) P7 226	P7: I think being mindful of, of what is, is really in there that's causing distress or a measure of upset.
	I: So you're pointing and touching your chest here, inside you?
Defn: self-compassion means allowing 'it'?& nurturing healing and soothing P7 230 Self-compassion is an individual experience P7 230	P7: Inside, and, and not trying to squeeze it out and suppress it, but to acknowledge it and, and actually try and nurture a form of…I don't know if healing is the right word, but but sort of soothing, yes, yes…presumably it's different for everybody to an extent.

2. Example of deductive coding for Phase Two for 'Barriers'

2P1 28	This has been quite a learning experience, in that sometimes I feel there is no time to undertake the exercises; then realising this is going assist greatly and I should be doing more not less!
2P1 20	Although it's been pretty much a 'stop/start' in commencing the programme due to my current situation,
2P5 54	*Did anything get in the way of you becoming kinder and more self-compassionate to yourself?* Time. Habit of putting others need first. An unwillingness to use the computer to access the videos and relaxation exercises.
2P7 19	Sorry I haven't sent in last module review but things have been hectic last few weeks. In fact husbands has deteriorated last few days and even more last night
2P3 53	yes of course carers are busy but I also think carers, particularly those caring for the terminally ill have trouble identifying themselves as carers with long term needs of their own. I have been at this for years with many more years to come and I still find it hard when asked 'what do you do' to respond with 'I am a carer '....it's a role which has no box to fit into in the ordinary world.
2P6 65	Time is the biggest issue, often when you have some time you are too tired / drained to be bothered trying which is why I find the simple exercises most effective.

Appendix 9: Examples of Thematic Maps

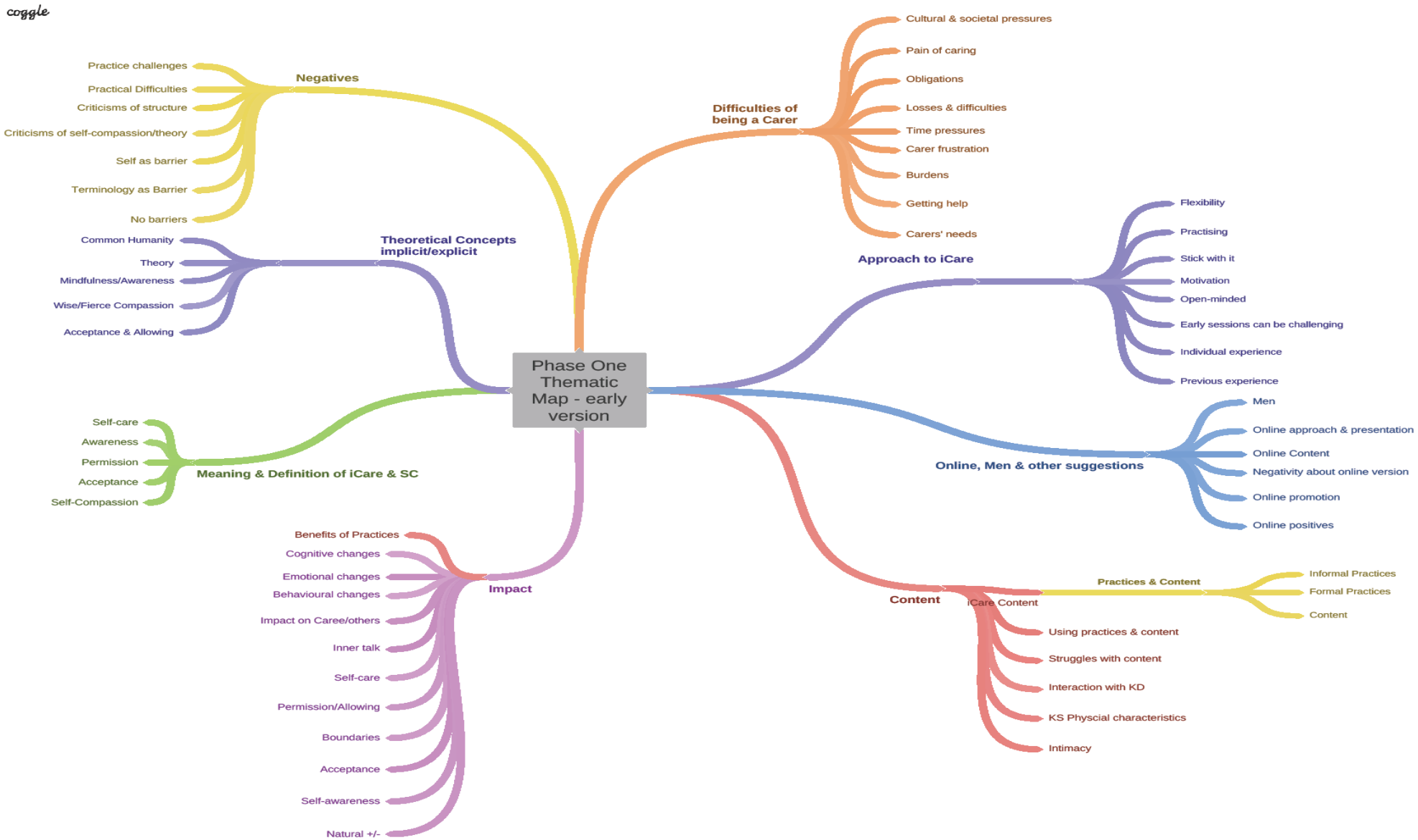
1. Phase One Thematic Map- Early stages of development with eight themes and 60 sub-themes

2. Phase One Thematic Map – Revised Version with four themes and 11 sub-themes

3. Phase One Thematic Map – Final Version with four themes and ten sub-themes

4. Phase Two Thematic Map – Early stages of development with four themes and 14 sub-themes

5. Phase Two Thematic Map – Final Version with four themes and ten sub-themes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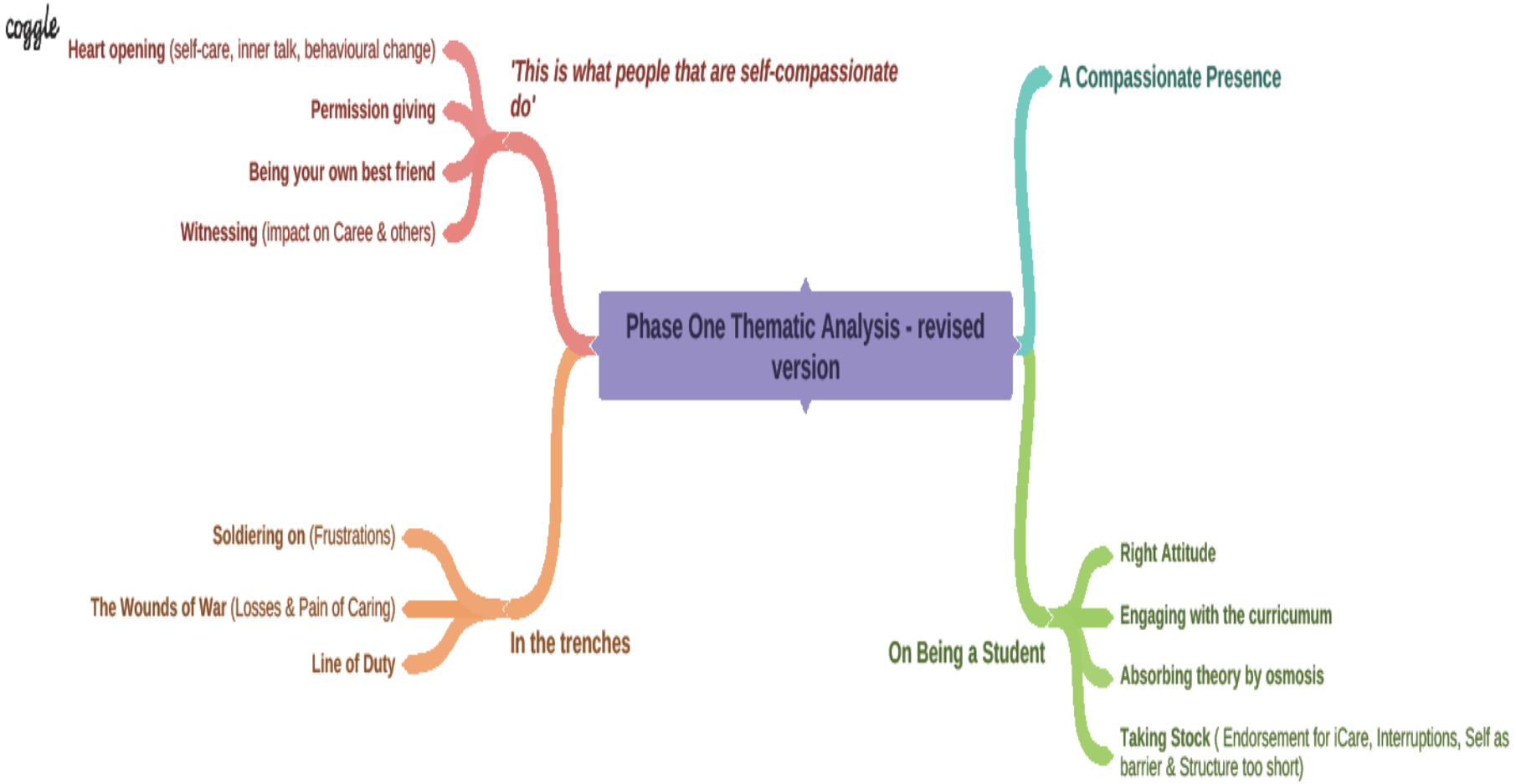
Phase One Thematic Map - early version
Negatives
Practice challenges
Practical Difficulties
Criticisms of structure
Criticisms of self-compassion/theory
Self as barrier
Terminology as Barrier
No barriers
Theoretical Concepts implicit/explicit
Common Humanity
Theory
Mindfulness/Awareness
Wise/Fierce Compassion
Acceptance & Allowing
Meaning & Definition of iCare & SC
Self-care
Awareness
Permission
Acceptance
Self-Compassion
Impact
Benefits of Practices
Cognitive changes
Emotional changes
Behavioural changes
Impact on Caree/others
Inner talk
Self-care
Permission/Allowing
Boundaries
Acceptance
Self-awareness
Natural +/-
Difficulties of being a Carer
Cultural & societal pressures
Pain of caring
Obligations
Losses & difficulties
Time pressures
Carer frustration
Burdens
Getting help
Carers' needs
Approach to iCare
Flexibility
Practising
Stick with it
Motivation
Open-minded
Early sessions can be challenging
Individual experience
Previous experience
Online, Men & other suggestions
Men
Online approach & presentation
Online Content
Negativity about online version
Online promotion
Online positives
Content
iCare Content
Practices & Content
Informal Practices
Formal Practices
Content
Using practices & content
Struggles with content
Interaction with KD
KS Physcial characteristics
Intimacy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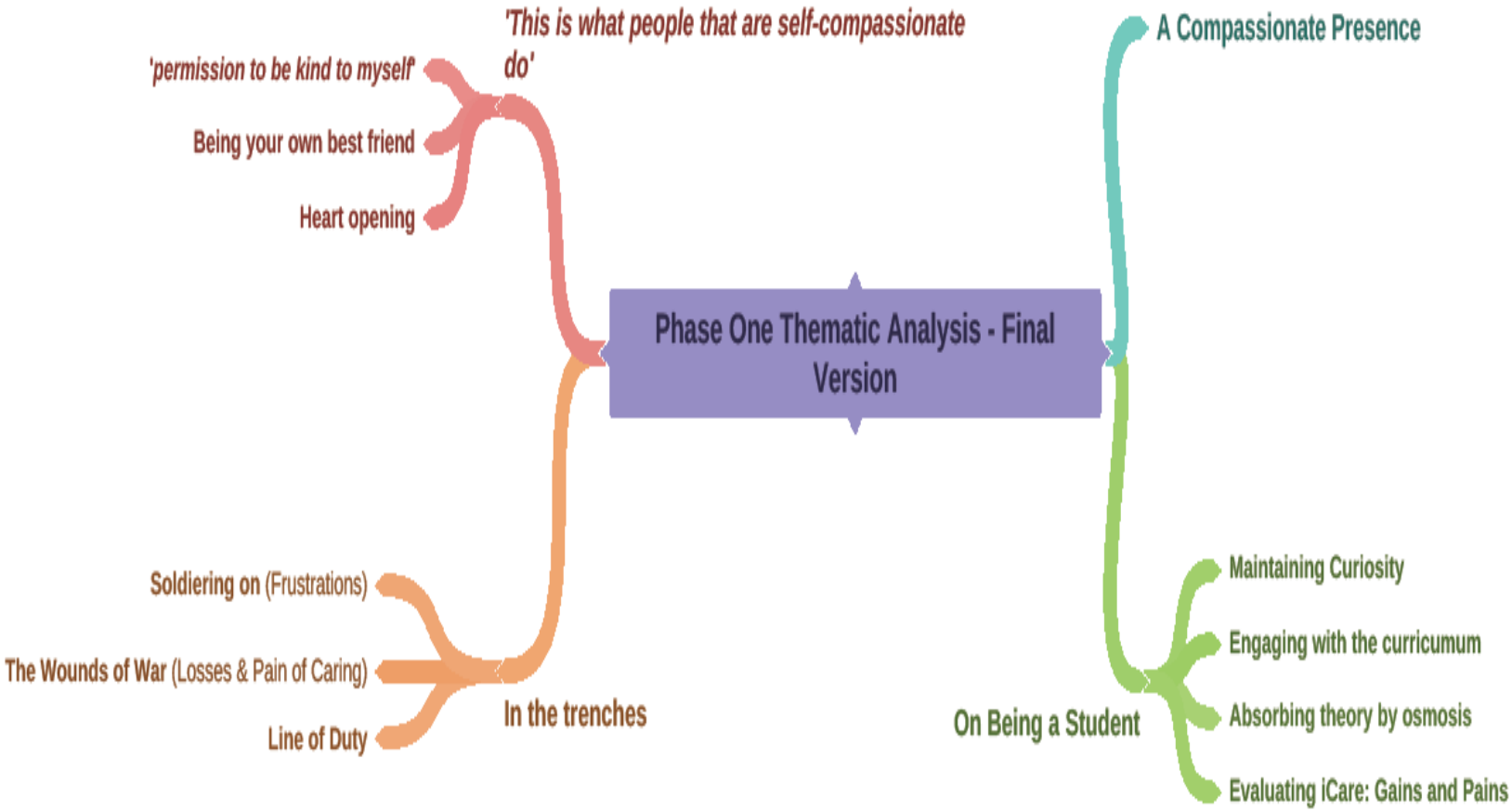
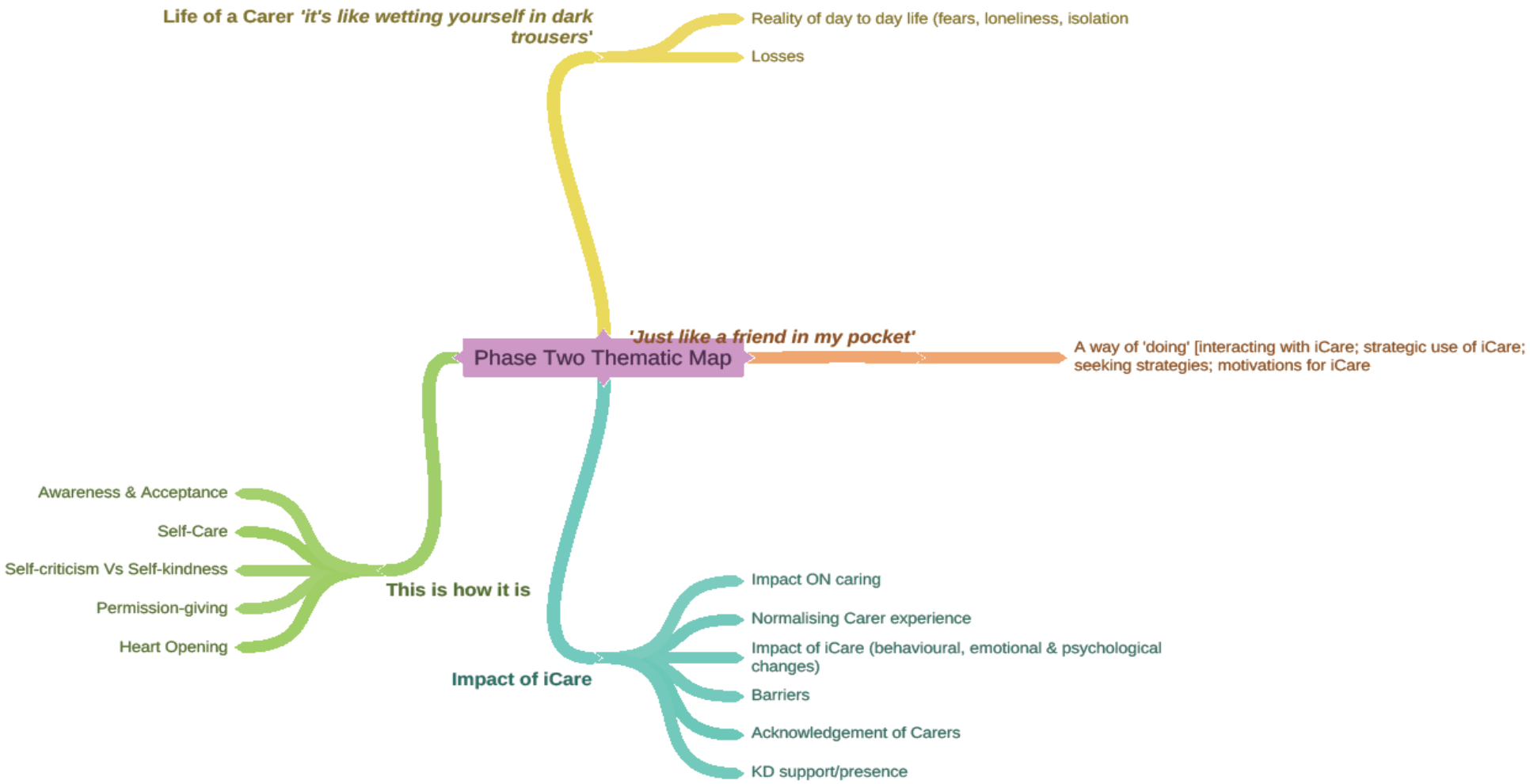
Heart opening (self-care, inner talk, behavioural change)
Permission giving
Being your own best friend
Witnessing (impact on Caree & others)
'This is what people that are self-compassionate do'
A Compassionate Presence
Phase One Thematic Analysis - revised version
Soldiering on (Frustrations)
The Wounds of War (Losses & Pain of Caring)
Line of Duty
In the trenches
On Being a Student
Right Attitude
Engaging with the curricumum
Absorbing theory by osmosis
Taking Stock (Endorsement for iCare, Interruptions, Self as barrier & Structure too short)

coggle


Phase One Thematic Analysis - Final Version
'This is what people that are self-compassionate do'
'permission to be kind to myself'
Being your own best friend
Heart opening
In the trenches
Soldiering on (Frustrations)
The Wounds of War (Losses & Pain of Caring)
Line of Duty
A Compassionate Presence
On Being a Student
Maintaining Curiosity
Engaging with the curricumum
Absorbing theory by osmosis
Evaluating iCare: Gains and Pains

coggle

Phase Two Thematic Map- Early Version



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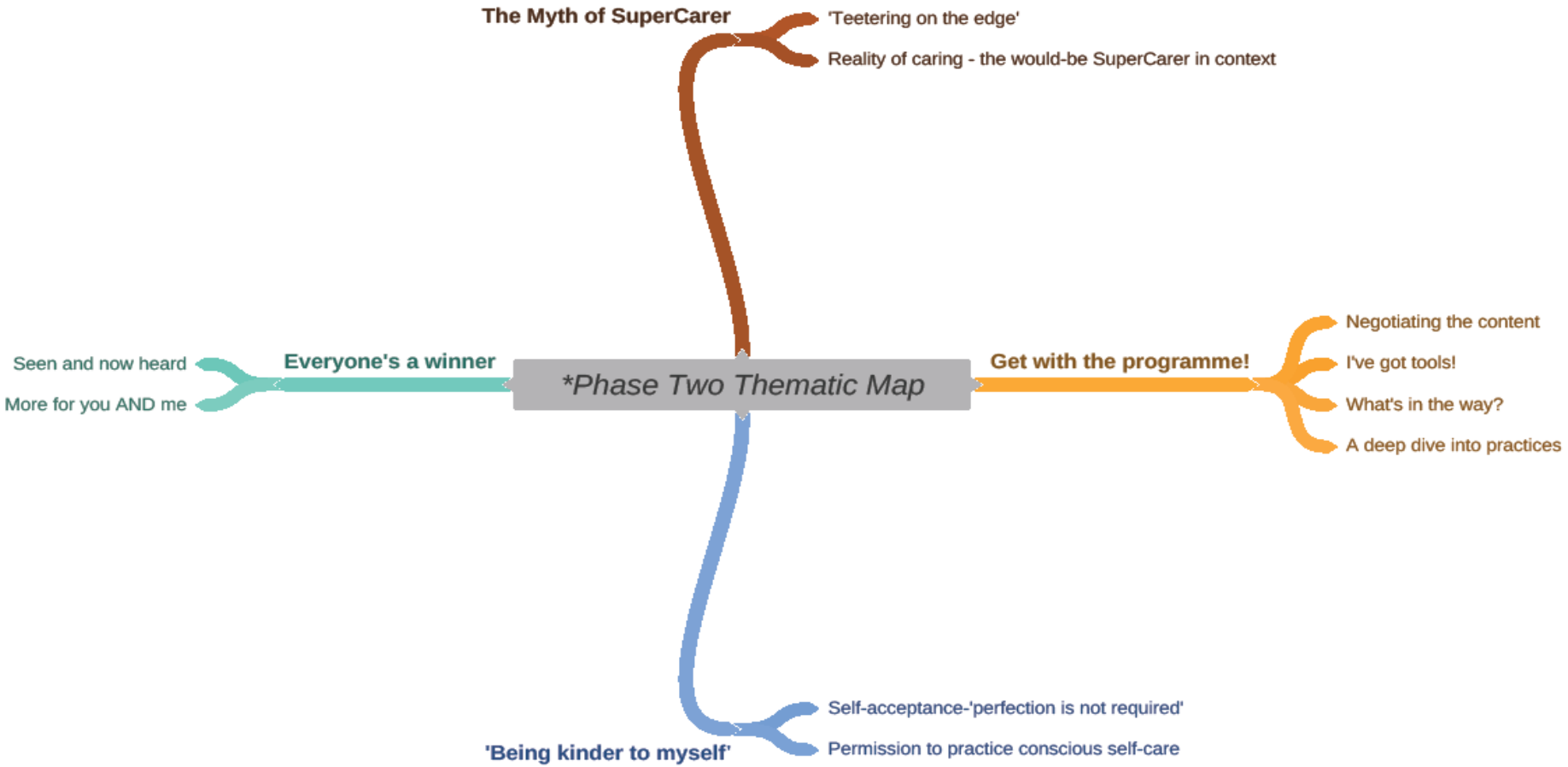
Phase Two Thematic Map - Final Version



Appendix 10: Pilot Online Participant Information Sheet, Consent Form & Biographical Information Form

Participant Information Sheet

Researching an online mindfulness and self-compassion programme for carers of those with a life limiting or palliative diagnosis

Dear Carer

Thank you for indicating that you are interested in taking part in this research. This Information Sheet will hopefully explain what is involved, but if you need further clarification, then please do not hesitate to contact me using the contact details below.

What is the purpose of the study?

This research is part of my doctoral thesis that I am undertaking at the University of Chester. Being a carer of those with life limiting illnesses e.g. certain cancers, motor neurone disease, dementia or multiple sclerosis, can be very stressful. Increasing carers' ability to manage their own needs and take greater care of themselves may help them to stay resilient and healthy in the face of stress. One way of developing this ability is through an **online mindfulness and self-compassion training programme** called **iCare**. It is a four module programme designed to **develop well-being, manage stress, burnou**t and **compassion fatigue** using mindfulness and self-compassion practices.

You are being invited to participate in the iCare programme as you are a carer and I would be very interested in exploring your views on, and experience of, this programme.

Who can take part?

Anyone who is currently involved as a carer to an individual who has a life-limiting or terminal illness can participate. A life limiting illness is one that is known to shorten people's lives. These types of illnesses include, among others, heart failure, liver failure, lung disease, motor neurone disease, multiple sclerosis, dementia, HIV/Aids, certain

forms of cancer, spread of cancer and recurrence of cancer that has previously responded to treatment.

A carer is someone who cares, unpaid, for a friend or family member who due to a life-limiting or terminal illness, cannot cope without their support. Caring can include:

• Practical household tasks such as cooking, cleaning, washing up, ironing, paying bills and financial management.

• Personal care such as bathing, dressing, lifting, administering medication and collecting prescriptions.

• Emotional support such as listening, offering advice and friendship

Please note if the person you care for is aged under 18, or you yourself are under the age of 18 or the person you care for has a chronic disease or disability which does not limit life expectancy then you will not be able to participate in this particular study.

What would be involved?

You will be invited to participate in the four module iCare online programme which means that you will need to have a computer or tablet to access the programme. iCare will be hosted on an online platform through my website (www.katediggory.com). Each module will contain:

- A brief video where I talk about mindfulness and self-compassion principles and/or lead you through an exercise together with supportive explanatory notes where applicable
- A recording of a guided exercise or meditation for you to listen to for the next seven days, but this is not mandatory. You will also be able to download this onto your mobile, computer or tablet if you want to. The daily maximum practise commitment is around 20 minutes.

- I will also ask you for brief online feedback as you go through iCare to see how you are finding the programme.

Before you start iCare you will also be required to give your consent to participation in this research and you will also need to complete two short forms designed to capture your current levels of self-compassion (the Self-Compassion Scale - 'SCS') and whether you are currently experiencing depression, anxiety or stress (Depression, Anxiety & Stress Scales - 'DASS'). These should take no longer than 10 minutes to complete.

After you have finished the programme, approximately two weeks later, I will send you a link to an online questionnaire which is enquiring about your experience of the online iCare programme. This should take no longer than 25 minutes to complete. You will also be asked to complete the SCS & DASS forms again.

Your right to withdraw without prejudice

You have every right to withdraw from the study at any stage, up to when I start to write up my thesis. Even if you choose to withdraw from the research you will still be able to participate in the iCare programme.

What are the possible disadvantages and risks of taking part?

One disadvantage of taking part in this research is the cost of your time. There is a small possibility that participating in the iCare programme may cause upset or raise emotive issues. In these circumstances I am also able to provide you with a list of therapists in your locality whom you may be able to access for support. Carers UK also have a Help and Advice line: 0808 808 7777

What are the possible benefits of taking part?

Potential benefits include the opportunity to learn new skills and practices to build your resilience and manage stress in your role as a carer. Additionally, through participation in the research you may be helping to influence future support for carers.

What if something goes wrong?

I will do everything within my ability to ensure your safety and confidentiality. However, if you are not happy with any aspect of the research process, please raise it with me. If you are still not happy, you may raise it with my Research Supervisor, Dr Andrew Reeves, at the University of Chester: https://www.chester.ac.uk/sps/staff/dr-a-reeves

If you are still unhappy with things, you may then raise it with the Dean of Faculty, Professor David Balsamo: Email: d.balsamo@chester.ac.uk. In the unlikely event that you are harmed by taking part in the research, there are no special compensation arrangements in place, in accordance with the University of Chester Research Governance Handbook.

Will my taking part in the study be kept confidential, and how will my data be stored?

The fact that you are taking part in the research, and everything that you share, will remain confidential. The data you provide online (such as brief biographical data, completed SCS and DASS forms, any communications we have via www.katediggory.com about your experience of iCare and the final questionnaire) will be held on two platforms Online Surveys (/www.onlinesurveys.ac.uk/) and through www.katediggory.com, which is a web site hosted by www.Wix.com. Both platforms are hosted on secure, encrypted servers and have privacy policies which can be found at https://www.onlinesurveys.ac.uk/help-support/online-surveys-security/ and https://www.wix.com/about/privacy. Additionally you can find my privacy policy at https://www.katediggory.com/privacy-policy. Every effort will be made to maintain the confidentiality of your data but I am unable to guarantee absolute confidentiality of your personal information provided online because I do not control Online Surveys and www.wix.com. However I am confident that these are reputable companies.

In the unlikely event that Child Protection issues are raised, I may have to alert Social Services or Police, but otherwise, what you share will form part of the data which will be anonymised by use of a pseudonym or code. The data will be stored securely in locked

premises and kept encrypted on a password protected computer. Only I, and my Research Supervisor, will have access to the data. The data will be destroyed (shredded or electronically deleted) after 10 years, in keeping with the Data Protection Act.

What will happen to the results of the research study?

The completed research will be stored (bound and electronic) at the University of Chester. The research will be disseminated in future publications and at conferences.

What do I do now?

Please complete the following Consent to Participate questions, the Biographical Details form and the two Questionnaires and then you will be ready to start iCare!

Researcher	**Supervisor**
Kate Diggory	Dr Andrew Reeves
kate@katediggory.com or Mob: xxxxx xxxxxx	xxxxxxx xxxxx xxxxxx
University of Chester	University of Chester
Division of Counselling and Psychotherapy Dept. of Social and Political Science University of Chester Parkgate Road Chester CH1 4BJ	Division of Counselling and Psychotherapy Dept. of Social and Political Science University of Chester Parkgate Road Chester CH1 4BJ

I have read and understood the participant information sheet and have had the chance to ask questions.

- Yes
- No

I understand that my participation is voluntary and that I am free to withdraw at any time up until the point of writing up the thesis, without giving any reason

- Yes
- No

I agree to take part in this study and have the right to withdraw from the study at any stage up to the point of writing up the thesis. I understand that by withdrawing from the research, this does not affect my access to the iCare programme, which will remain available to me.

- Yes
- No

I understand that the data will be written up as part of a thesis and I will not be identifiable in the thesis.

- Yes
- No

I have answered 'Yes' to the above questions

Page 3: Page 1

Confidential Participant Biographical Details

All personally identifiable details will be kept confidential.

Please answer the following questions

Only Carers who live in the UK (England, Scotland, Wales & Northern Ireland) are eligible to participate in this research. **Do you live in the UK?**: *Required*

- Yes, I live in the UK
- No, I live outside the UK

Page 4

What is your full name? *Required*

Your answer should be no more than 100 characters long.

What is your Date of Birth? *Required*

Dates need to be in the format 'DD/MM/YYYY', for example 27/03/1980.

What best describes your gender?: *Required*

Please select exactly 1 answer(s).

- [ ] Female Male
- [ ] Prefer not to say Prefer to
- [ ] self-describe
- [ ]

If you selected 'Prefer to self-describe' please use this box for your response

Your answer should be no more than 200 characters long.

Please provide your Email address: *Required*

Your answer should be no more than 100 characters long.

Please provide the date of birth of the person you are caring for:

Dates need to be in the format 'DD/MM/YYYY', for example 27/03/1980.

What best describes the gender of the person you are caring for?:

- Female Male
- Prefer not to say Prefer
- to describe
-

Use the box below to describe the gender of the person you are caring for

Your answer should be no more than 97 characters long.

What is the diagnosis of the person you are a Carer for: *Required*

Your answer should be no more than 200 characters long.

When where they first diagnosed (approximate date is fine): *Required*

Your answer should be no more than 200 characters long.

What is your relationship to the person you care for e.g. partner, wife, husband, sibling, friend, neighbour?: *Required*

Your answer should be no more than 100 characters long.

Do you have a regular practice of meditation *Required*

- Yes
- No

What type of meditation do you practice and how long have you been practising?

Your answer should be no more than 300 characters long.

What is your ethnic group? Please choose one option that best describes your ethnic group or background *Required*

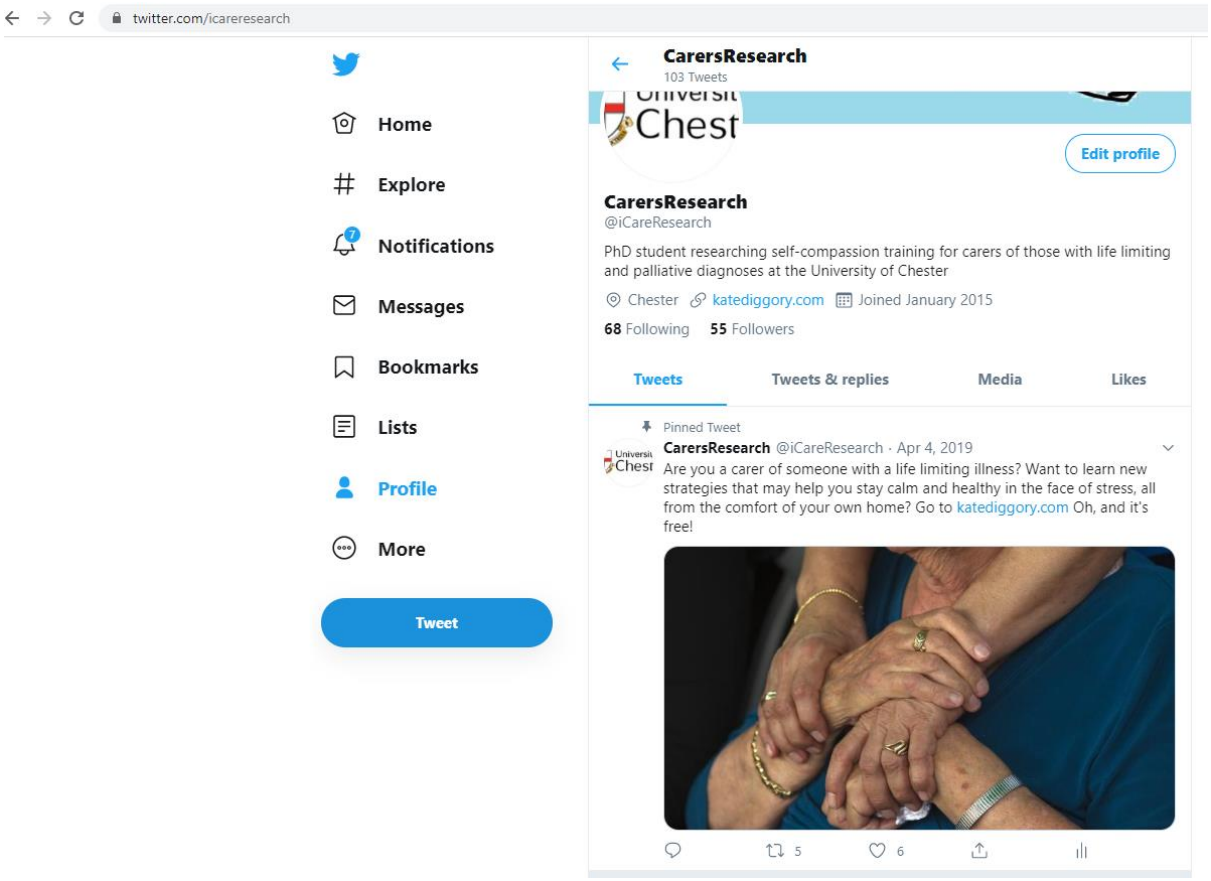
- White English White
- Welsh White Scottish
- White Northern Irish
-

- White British Irish
- Gypsy or Irish Traveller
- Any other White background White
- and Black Caribbean White and Black
- African White and Asian
- Any other Mixed/Multiple ethnic background Indian
- Pakistani Bangladeshi
- Chinese
- Any other Asian background Black
- British
- African
- Caribbean
- Any other Black/African/Caribbean background Arab
- Any other ethic group Other
-
-
-
-
-

If you selected: **Other** or **Any other White background** or **Any other Mixed/Multiple ethic background** or **Any other Asian background** or **Any other Black/African/Caribbean background** or **Any other ethnic group**, please describe below:

Your answer should be no more than 200 characters long.

Appendix 11: Pinned Tweet Phase Two



Appendix 12: Participant Information Sheet Phase Two

University of Chester

Participant Information Sheet

Researching an online mindfulness and self-compassion programme for carers of those of those with a life limiting or palliative diagnosis

Dear [Carer]

Thank you for indicating that you are interested in taking part in this research. This Information Sheet will hopefully explain what is involved, but if you need further clarification, then please do not hesitate to contact me using the contact details below.

What is the purpose of the study?

This research is part of my doctoral thesis that I am undertaking at the University of Chester. Being a carer of those with life limiting illnesses e.g. certain cancers, motor neurone disease, dementia or multiple sclerosis, can be very stressful. Increasing carers' ability to manage their own needs and take greater care of themselves may help them to stay resilient and healthy in the face of stress. One way of developing this ability is through an **online mindfulness and self-compassion training programme** called **iCare**. It is a four module programme designed to **develop well-being, manage stress, burnou**t and **compassion fatigue** using mindfulness and self-compassion practices.

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A carer is someone who cares, unpaid, for a friend or family member who due to a life-limiting or terminal illness, cannot cope without their support. Caring can include:

• Practical household tasks such as cooking, cleaning, washing up, ironing, paying bills and financial management.
• Personal care such as bathing, dressing, lifting, administering medication and collecting prescriptions.
• Emotional support such as listening, offering advice and friendship

Please note if the person you care for is aged under 18, or you yourself are under the age of 18 or the person you care for has a chronic disease or disability which does not limit life expectancy then you will not be able to participate in this particular study.

What would be involved?

You will be invited to participate in the four module iCare online programme which means that you will need to have a computer or tablet to access the programme. iCare will be hosted on an online platform my web site (www.katediggory.com). Each module will contain:

- A brief video where I talk about mindfulness and self-compassion principles and/or lead you through an exercise
- A downloadable sheet of explanatory notes for that module
- A recording of a guided exercise or meditation for you to listen to for the next seven days, but this is not mandatory. You will also be able to download this onto your mobile, computer or tablet if you want to. The daily maximum practise commitment is around 20 minutes.
- I will also ask you for brief online feedback as you go through iCare to see how you are finding the programme.

Before you start iCare you will also be required to give your consent to participation in this research and you will also need to complete two short forms designed to capture your current levels of self-compassion (the Self-Compassion Scale - 'SCS')

and whether you are currently experiencing depression, anxiety or stress (Depression, Anxiety & Stress Scales - 'DASS'). These should take no longer than 10 minutes to complete.

After you have finished the programme, approximately two weeks later, I will send you a link to an online questionnaire which is enquiring about your experience of the online iCare programme. This should take no longer than 25 minutes to complete. You will also be asked to complete the SCS & DASS forms again.

Your right to withdraw without prejudice

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What are the possible disadvantages and risks of taking part?

One disadvantage of taking part in this research is the cost of your time. There is a small possibility that participating in the iCare programme may cause upset or raise emotive issues. In these circumstances I am also able to provide you with a list of therapists in your locality whom you may be able to access for support. Carers UK also have a Help and Advice line: 0808 808 7777

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What if something goes wrong?

I will do everything within my ability to ensure your safety and confidentiality. However, if you are not happy with any aspect of the research process, please raise it with me. If you are still not happy, you may raise it with my Research Supervisor, Dr Andrew Reeves, at the University of Chester: https://www.chester.ac.uk/sps/staff/dr-a-reeves
If you are still unhappy with things, you may then raise it with the Dean of Faculty, Professor David Balsamo: Email: d.balsamo@chester.ac.uk. In the unlikely event that you are harmed by taking part in the research, there are no special compensation arrangements in place, in accordance with the University of Chester Research Governance Handbook.

Will my taking part in the study be kept confidential, and how will my data be stored?

The fact that you are taking part in the research, and everything that you share, will remain confidential. The data you provide online (such as brief biographical data, completed SCS and DASS forms, any communications we have via www.katediggory.com about your experience of iCare and the final questionnaire) will be held on two platforms Online

Surveys (/www.onlinesurveys.ac.uk/) and through www.katediggory.com, which is a web site hosted by www.Wix.com. Both platforms are hosted on secure, encrypted servers and have privacy policies which can be found at https://www.onlinesurveys.ac.uk/help-support/online-surveys-security/ and https://www.wix.com/about/privacy. Additionally you can find my privacy policy at https://www.katediggory.com/privacy-policy. Every effort will be made to maintain the confidentiality of your data but I am unable to guarantee absolute confidentiality of your personal information provided online because I do not control Online Surveys and www. wix.com. However I am confident that these are reputable companies.

In the unlikely event that Child Protection issues are raised, I may have to alert Social Services or Police, but otherwise, what you share will form part of the data which will be anonymised by use of a pseudonym or code. The data will be stored securely in locked premises and kept encrypted on a password protected computer. Only I, and my Research Supervisor, will have access to the data. The data will be destroyed (shredded or electronically deleted) after 10 years, in keeping with the Data Protection Act.

What will happen to the results of the research study?

The completed research will be stored (bound and electronic) at the University of Chester. The research will be disseminated in future publications and at conferences.

What do I do now?

If after reading this Information Sheet you are interested in taking part in this research please contact either me or my research supervisor using the details below:

Researcher	Supervisor
Kate Diggory	Dr Andrew Reeves
Xxxxxx@chester.ac.uk or Mob: xxxxx xxxxxx	xxxxxxx@chester.ac.uk xxxxx xxxxxx
University of Chester Division of Counselling and Psychotherapy Dept. of Social and Political Science University of Chester Parkgate Road Chester CH1 4BJ	University of Chester Division of Counselling and Psychotherapy Dept. of Social and Political Science University of Chester Parkgate Road Chester CH1 4BJ

Thank you so much for your interest in this research. Kate Diggory

Appendix 13: Recruitment Poster Phase Two

Appendix 14: Online Qualitative Questionnaire Phase Two

1. What prompted you to sign up for the iCare programme? *Required*

2. Now that you have completed the iCare programme what changes (if any) have you noticed in:

2.a. How critical you are in the way you talk to yourself? *Required*

2.b. The ways you are practising self-care? *Required*

2.c. Your mood? *Required*

2.d. How you carry out your caring role? *Required*

3. What did you gain (if anything) from participating in iCare? *Required*

4. Did anything get in the way of you becoming kinder and more self-compassionate to yourself? *Required*

Here's a short reminder of what was covered in the four iCare Modules:

Module 1 - Soothing Touch, Body Scan, Introduction to Mindfulness, Paul Gilbert's 3 emotional systems model

Module 2 - Affectionate Breathing, Mindful Pause, Self-Compassion Break, Myths of Self-Compassion

Module 3 - Giving and Receiving Compassion, Caregivers' meditation, Caregiver fatigue, Exploring Compassion, Empathy & Pity

Module 4 - Loving Kindness for Difficult Times, Gratitude & Savouring, How to support yourself going forwards

5. What (if anything) did you find useful from any of the modules and if so why?

Required

6. Looking back over the modules what didn't work for you (if anything)? Please explain why something didn't work *Required*

7. Is there anything that you particularly want to remember from the iCare programme? *Required*

8. How could iCare be improved? *Required*

9.

If another carer stopped you and said tell me about the online iCare programme because I might be interested in it, what would you say? *Required*

10. Having been through the iCare programme what does the term 'self-compassion' mean to you? *Required*

11. If you have any other comments you would like to make please feel free to write them here

Page 2: One Last Thing - Repeating the Two Questionnaires

Before you go could you please complete the two questionnaires that you filled out at the start of iCare (the Mindful Self-Compassion Scale and the Depression, Anxiety & Stress scales). This will help me to assess whether there has been any change in your mood following iCare and in your levels of self-compassion. They won't take much longer than 10 minutes to complete and then that is the end of the research project!